*Motto:* "Őrzők, vigyázzatok a strázsán, Az Élet él és élni akar" Ady Endre<sup>\*</sup>

# Hungarian National Cancer Control Programme

BUDAPEST FEBRUARY 2006

<sup>\* &#</sup>x27;Sentries, stand sentinel, Life lives and wants to live' — Endre ADY

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## **BACKGROUND AND OBJECTIVE**

Given the extremely unfavourable conditions in Hungary compared to other countries, the government of the Republic of Hungary is determined to permanently reduce malignant neoplastic diseases (hereinafter: cancer) as quickly as possible. Its goals are to cut back the difficulties caused by tumours, reduce morbidity and mortality indices, and to improve quality of life for patients and their families. It plans to do this through complex, coordinated society-wide cooperation that includes all affected disciplines and addresses all involved groups of people. The aim is to transform current practices to achieve a complex oncological outlook, to shape and operate an effective treatment system that offers balanced efficient patient care. Following the guidelines and recommendations of the World Health Organization's (hereinafter: WHO) National Cancer Control Programmes we are initiating our own Hungarian National Cancer Control Programme.

The programme is imbedded in the Hungarian epidemiological situation and current Hungarian conditions of cancer patient care and it makes proposals for concrete measures, relying on the guidelines of the health administration. Implementation of the programme requires a new outlook and practices on the part of the government, the public and healthcare professionals. It also will be necessary to evolve new structures to attain both short-term improvements in quality of life and boost the efficiency and aptitude of the treatment system, as well as achieve tangible results as illustrated in an improvement in mortality indices within 10-15-years' time.

The programme document includes an analysis of the epidemiological situation of neoplastic diseases along with primary and secondary prevention strategies. It offers a review of Hungarian care for cancer patients and of the problems of organizing their care, and then proposes the structural, legal, and financing changes that are necessary.

The programme is expected to establish a healthier environment in which the incidence of cancer will decline, a more humane, better-equipped care system that operates up to contemporary standards will evolve, and up-to-date diagnostics will promote quick and effective complex treatment. The result, we are certain, will be a drop in prevalence, an improvement in patient care, better quality of life for patients and their families, easier readjustment to family and society, a drop in mortality, and better care, support, and qualify of life for the terminally ill.

# SITUATION ANALYSIS

## **1. EPIDEMIOLOGY OF CANCER IN HUNGARY**

Sadly, Hungary's cancer mortality statistics have been dramatically elevated for a long time. At present, there are about 300,000 cancer patients and in 2003, 33,530 people died of malignant neoplastic diseases. Cancer is the second most frequent cause of death following cardiovascular diseases. Given the biological nature of tumours, combating them is a hard and many-faceted struggle. They occur so frequently that the prevention, up-to-date treatment, and control of cancer have become public health issues.

#### Comparative Hungary-Europe analysis of cancer mortality statistics,

The Central Statistical Office registers tumour mortality statistics. Age-adjusted standard mortality rate can be used to define the tumour mortality trend since it eliminates the rise in the number of tumours associated with increased age. The Central Statistical Office provides data to the World Health Organisation. These figures are the basis for the epidemiological analyses published in international literature, which indicate that *Hungary has the highest rate of mortality due to cancer in Europe*. An analysis of European cancer statistics and the resulting conclusions offer guidelines in designing Hungarian cancer control strategies. An analysis of the age-adjusted mortality rates of 36 European countries demonstrated that Hungary is in first place in male mortality due to cancer while the female mortality rate due to all types of cancer is second on the continent. A comparison between Hungary's cancer mortality data and the corresponding data of the rest of Europe leads to the conclusion that Hungary leads the male mortality statistics in smoking-related lung and oral cavity cancer. At the same time, Hungary is in 1<sup>st</sup> place in female mortality due to colorectal cancer and leukaemia, and in 9<sup>th</sup> place in breast cancer mortality.

Hungary's male mortality rate due to cancer is exceptionally high, even when compared to the rest of Central Europe. Hungary is followed by the Czech Republic, and Poland is third. Mortality rates due to cancer in Central Europe, including Hungary, are high as a consequence of cigarette smoking, excessive alcohol consumption, and fluctuations in the standards of care received by cancer patients from one part of the country to the next. In Hungary, prevention, early diagnosis, more up-to-date diagnostic methods, and effective therapies are expected to be the primary tools in reducing mortality.

#### Incidence rate of malignant tumours in Hungary

In 2000-2003, the number of cancer among the male population increased from 34,359 to 40,366. A breakdown of types of tumour showed that in 2000, lung cancer led the list at 20.5 percent. Colorectal cancer accounted for 13.0 percent of overall tumour morbidity, while oral cavity cancer was third in incidence at 8.1 percent. In 2000-2003, the rate of morbidity due to lung cancer rose from 145.1 to 155.9 per 100,000 population, while colorectal cancer increased from 92.1 per 100,000 population to 100.2. Increases in the number of reported cases of prostate and skin cancer also contributed to the rise in incidence, and this reflects an improvement in data reporting.

In 2000-2003, the number of female cancer registered rose from 32,751 to 40,184. Breast cancer led the morbidity list with 20.3 percent-21.3 percent. This was followed by colorectal cancer at 12 percent. Lung cancer was in third place with 9.5 percent. The increase in lung cancer morbidity was particularly noteworthy, rising from 58.2 per 100,000 population to 70.7 in the three years.

The number of diagnosed female breast cancer increased by 1,888 cases. The rise in cases is probably linked to organized breast cancer screening that was introduced in 2001. One favourable point is that there was a rise in the number of in situ breast cancer diagnosed early among the new cases, for this significantly improves chances of recovery. At the same time, it is unfortunate that the number of cases of female lung cancer rose to 3,543 in 2003, from 3,116 in 2000. Data broken down by age showed that lung cancer occurred even in the 35-40 age-group, that tobacco smoking taken up at a young age is highly prevalent in Hungary. It is worth noting that within the incidence of cervical cancer, 30 percent of reported cervical cancer were in situ carcinoma, the early diagnosis of which could significantly reduce cervical cancer mortality. Using Hungarian cancer morbidity and mortality data, cancer control programmes can be outlined quite clearly.

If preventive opportunities are not taken advantage of, then, according to some estimates and relying on 'age-specific' data, in the years to come, 313 of every 1,000 newborn males and 149 of every 1,000 newborn females will die of a malignant tumour before the age of 75 years.

## **National Cancer Register**

Accurate information on cancer mortality data is essential to designing an effective Cancer Control Programme. Malignant tumours are reported to the National Cancer Register by the healthcare institutions.

Established by the World Bank's "close the gap programme" the National Cancer Register began operations in line with international guidelines in 2000. The National Cancer Register receives regular data on cancer from 198 medical facilities. Thanks to stronger discipline in reporting, the quality of data processing is improving. However, it is extremely necessary to professionally supervise the credibility of the Cancer Register and improve it continuously to guarantee its acceptability on international level. It would be desirable to expand the role of the Register to collect survival figures and begin analyses, and to offer the option of reporting online.

From time to time, representative samples should be collected and evaluated to survey the accuracy of Cancer Register data.

Furthering professional reporting systems is a fundamental prerequisite of monitoring the results attained during the programme.

The data of all children who are cancer patients are registered in a reliable central registry by the *paediatric oncology centres*, so treatment outcomes may be monitored and evaluated according to type of disease, the centre where treatment is undertaken, and on nationwide level, as well.

## 2. THE STATUS OF PAEDIATRIC ONCOLOGY

Malignant tumours and leukaemia are significantly rarer in childhood than in adulthood, but they are of outstanding significance because:

- 1. cancer is the second leading cause of death after accidents among children aged 1-14 years,
- 2. if they are diagnosed in time and treated appropriately, the patients can recover and after reaching maturity, their own children will not develop cancer more frequently,

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  - 3. the loss of a child is so serious a blow to an entire family that it takes many long years to cope with it, if it is possible at all; it deteriorates quality of life and enjoyment of life for both parents and siblings.

All of society is deeply aware that no sacrifice is too great to reduce the number of cancer among children and to treat the children who do fall ill. Hungarian National Cancer Control Programme must update and upgrade its fight against childhood cancers.

In the past thirty years, the most significant progress in treating cancer internationally as well as in Hungary has been in the treatment of paediatric cases. While in the 1970s, only a fraction of patients recovered completely, today, on average, nearly two-thirds of children with cancer can be successfully treated. Of course, the type of tumour and correct treatment will determine actual survival chances. At present, one person out of every 1,000 who reaches young adulthood is the survivor of a childhood cancer.

## Incidence of paediatric cancers

We have accurate data on the number of paediatric malignancies. Hungary was among the first countries in Europe with this registry, for the registration and up-to-date uniform management of this data on nationwide level goes back to 1971. In 2004, there were 14 new cases per 100,000 children under the age of 15 (that is about 300 new cases a year), while the number of patients under treatment was 622 and the number in continuing care was 2,163. The incidence of paediatric malignancies is similar to Western Europe. One Hungarian specific feature is that the incidence of central nervous system tumours is about the same as that of leukaemia, with each accounting for one-third of all cancer. All other cancers make up the remaining third.

## **3. PREVENTION OF CANCER DEVELOPMENT**

## 3.1 Primary prevention

To this day, we cannot identify all the causes of most cancers. Throughout the world, thousands of researchers are doing exhaustive work to uncover evidence of the factors that trigger the start of cancerous processes. We do know that we are not seeking a single cause, for there are numerous internal and external factors that need to come together and combine with inherited mechanisms to trigger the onset of cancer.

One basic condition of sustainable development and economic competitiveness is the health of our human resources, of our people themselves. There are factors that repeatedly or regularly influence our natural and man-made environments that can lead to cancer. Physical factors of this sort include ionizing and non-ionizing radiation, noise and vibration. Chemical ones include various hazardous chemical agents that are carcinogenic, that damage reproduction, cause development disorders, that are immunotoxic, that destroy endocrine systems, that trigger allergies or - as dust - that damage the lungs (such as asbestos). Biological hazards include viruses and bacteria. There are also ergonomic pathogens that result in locomotor disorders. We also see an incidence of physical or emotional stress and the effects of increased psychosocial strain caused by pathological situations. These factors are the most common causes or triggers of endemic diseases (chronic non-communicable diseases including cancer) or they play a significant role in increasing their progression. According to

WHO sources, about 5-10 percent of cancer in industrialized countries are the result of workplace pathogens and 1-2 percent are caused by environmental pathogens.

Primary prevention means eliminating the effects that are known or assumed causal or risk factors and that play roles in the evolvement of cancer from the man-made or natural environments or ways of life of individual people. Primary prevention is a complex task that involves all of society. The results may only appear on long term, possibly only decades from now, but they require all of society's resources, going beyond the scope of healthcare and oncology.

One of the most important of the many reasons behind the unfavourable epidemiological situation is the insufficiency of primary prevention, for it is several decades behind the times. This is why we have been unable to effectively keep the carcinogenic factors of our environment away from our bodies and thus prevent the evolvement of malignancies.

The best way to learn healthy lifestyle-related information and adopt it on skill-level is in settings of daily life, in which the specifics of the various age groups – life cycles – are treated as fundamental factors. These skills are primarily in the realm of nutrition, exercise and a tobacco- free way of life. At the same time, protection of emotional health is clearly a particularly important factor, for people need to be able to evaluate themselves correctly and improve their decision-making abilities to be able to make healthy choices. Information on prevention concerns more than protecting and promoting health, for it also includes appropriate use of healthcare services, a lifestyle that includes knowledge of when to see a doctor, and the establishment of health culture that is conducive to participation in recommended screenings.

The education system plays an outstanding role in imparting that information.

In keeping with the above, health education for the public, encouragement of a healthy lifestyle, creation of a correct attitude towards health, evolving a healthy style of nutrition, preventing the evolvement of unhealthy addictions (tobacco, alcohol) or habits (such as excessive sunbathing) or helping people to give them up are equally important. It is also vital to promote a demand for and practice of personal hygiene and of the ability to avoid workplace and environmental pathogens.

We have to consider the damage to health caused by tobacco smoking, alcohol consumption, improper nutritional habits and excessive sunbathing. Each component of these factors is a lifestyle problem on society-wide level, requiring active health information and active education for health, cooperation among the media, the healthcare profession, the executive portion of government, and the legislature.

In its recommendations for 2002, the World Health Organisation underlines the following as key elements in cancer prevention and risk factors:

- combating tobacco smoking;
- healthy diets;
- preventing obesity, supporting sports and exercise;
- reducing alcohol consumption;
- providing vaccination against the Hepatitis B virus;
- avoiding the effects of excessive sunbathing.

The role of health policy is to initiate the dissemination of information on prevention through the schools, and to promote media coverage, through articles and programmes, of knowledge on risk factors and on ways of controlling them. It also needs to support antitobacco groups and other NGOs and social organizations (Hungarian League Against Cancer, National Federation of Cancer Patients, etc.) in their educational and information dissemination efforts.

## 3.1.1. Tobacco smoking and alcohol consumption

In Hungary, tobacco smoking and alcohol consumption are leading public health issues. Hungary is one of the leading countries in Europe in per capita cigarette and spirit consumption, which is obviously associated with the extremely high incidence rates of lung cancer, lip and oral cavity cancer, laryngeal cancer, bladder cancer, and digestive system cancer and the ensuing high mortality rates.

*Tobacco smoking.* Tobacco smoke is a plethora of carcinogenic agents. Of its roughly 4,000 components 438 are carcinogenic and significant amounts of nicotine, tar, carbon monoxide and components of polyaromatic hydrocarbons and nitroso compounds enter the lungs and other organs directly and through the bloodstream. Passive smokers are not exempt from the carcinogenic effects, either. They are at significant risk and are 20-30 percent more likely to contract lung cancer through their workplaces of families. Even ten years after quitting smoking, a former smoker runs a higher risk!

Tobacco smoking is an etiological factor in 25-30 percent of all cancer. A person who smokes tobacco runs three times the risk of a tumour (lung, head, neck, bladder, etc.) when compared to a person who does not. In fact, in 2003, more women in Hungary died of lung cancer than of breast or colorectal cancer. A survey conducted in the Member States of the European Union in 1990-1994 found that 34 percent of men and 24 percent of women regularly smoked tobacco. The rate was even higher in the 25-39 age-group. Here it was 55 percent of men and 40 percent of women, which will most likely result in a higher incidence of tobacco-related cancer. Therefore, cutting tobacco smoking and protecting non-smokers are basic pillars of the European Cancer Codex programme of prevention. In the European Union Member States, the anti-tobacco stance and action consist of mandatory laws and nonmandatory recommendations. WHO's International Framework Convention for Tobacco Control (FCTC) is helping to bring the issue of smoking reduction to the forefront of Hungarian thinking, too. Joining the European Union offered Hungary new opportunities to adopt the tobacco control measures of the other EU Member States. The Warsaw Declaration for a Tobacco-free Europe, 2002, was designed with the Member States participation of the European health ministers, and the European Strategy on Tobacco Control, 2002, designed by them, contains a number of proposals. The main ones are a ban on the promotion of tobacco products, increases in taxes on tobacco products, campaigns against smoking, and smoke-free public places. In 2003, Hungary signed the WHO Framework Convention for Tobacco Control, which is expected to boost the success of anti-tobacco efforts. Within it, we have undertaken to increase the limits on accessing tobacco products and to cut advertising, while enhancing informative and preventive efforts and programmes.

According to the Central Statistical Office, there are about 2.6 million smokers in Hungary (1.6 million men and 1.0 million women). Among women, the prevalence of regular smoking increased to 26.6 percent as of 1994. The tobacco-smoking trend among young people is also unfavourable. Central Statistical Office published a comprehensive report on smoking-related morbidity and mortality data. That analysis gave the tobacco-associated mortality rate of men at 28 percent of overall mortality in 1999 and at 9 percent for women. However, with the continuous rise in the prevalence of tobacco smoking among women, we have to expect a continued rise in female mortality due to lung cancer.

The European Union has declared a coordinated international effort to combat tobacco smoking, which Hungary has joined. Tobacco control measures cover a growing number of areas. However, our efforts to offer information to the public and persuade people to quit smoking have not been sufficiently successful. We have introduced stricter legislation to protect non-smokers, made all childcare facilities and schools smoke-free, and given workplaces the option of banning smoking in their facilities. We have introduced playful preschool and school programmes to prevent children from starting to smoke. We are building a professional network to help people to quit, and are gradually increasing excise taxes on tobacco products. Public opinion is changing albeit slowly. The prestige of a non-smoking way of life is increasing even though there has been no shift in the ratio of smokers to nonsmokers in past years (43 percent of men and 30 percent of women smoke tobacco).

Along with its regulatory role, government activity involving voluntary instruction and popularization of programmes to help smokers quit, as well as its efforts to teach 10-18-year-olds the tactics of "just saying 'no" is vital to that age group.

*Alcoholism.* Alcoholism, which is exceptionally high in Hungary by international comparison, puts a huge burden on all of society and on the healthcare system.

Alcoholism combined with tobacco smoking increases the risk of cancer, and the two risk factors combined make up 40-50 percent of overall cancer mortality in Hungary. Men account for double the rate of smokers and four times the rate of alcoholics as women, but the difference is declining as women's habits change. The result is that the prevalence and mortality rates due to lung, lip, oral cavity, throat, laryngeal, oesophageal, liver, and stomach cancers are rising among women.

Nothing less than information campaigns and health education raised to the level of Public Health Programmes can induce changes in lifestyle that will cut back the current levels of combined cigarette and hard liquor consumption. The programmes we need will focus primarily on reducing the alcohol consumption of children and adolescents, and on establishing attitudes of responsible moderation, with a primary focus on protecting at-risk groups.

#### 3.1.2. The role of obesity in cancer development

Obesity plays a significant role in triggering both cardiovascular diseases and cancer. As the Body Mass Index (BMI) increases  $(23kg/m^2 - 30 kg/m^2)$  there is a gradual rise in the risk of colorectal, breast, endometrial, kidney, and oesophageal cancer. For instance, the risk of a colorectal tumour on the part of a person with a BMI of 30 kg/m<sup>2</sup> is 100 percent higher than the risk of a person with a 23 kg/m<sup>2</sup> BMI. Obesity increases the risk of tumour.

Statistics show that 11 percent of patients with colorectal cancer, 9 percent with breast cancer and 37 percent with endometrial cancer had heightened BMIs. Therefore, a main task in prevention is to underline the importance of avoiding obesity, which is attainable with healthy nutrition and appropriate exercise.

*Physical activity*, which means any type of movement on the part of an individual that uses energy, is an important tool in maintaining the body's energy balance. Physical activity reduces the risk of tumour development.

Regular exercise helps to maintain ideal weight and together with other interlinked biological mechanisms, it helps to reduce the risk of tumour development. In the past twenty years, the rate of overweight and obese children and adults has increased continuously. Obesity, in turn, increases the frequency of cancer development.

## 3.1.3. The role of nutrition in cancer development

The relationship between *nutrition* and health/disease has been well known for a long time. Low fat high fibre foods, and fruit, vegetables and whole grains reduce the risk of many types of cancer. Children need proportionately less fibre than adults do. For children, high fibre diets need to be introduced gradually. Too much fibre can make them feel full, resulting in an insufficient intake of energy, vitamins, and minerals.

Antioxidants neutralize free radicals. Free radicals are natural by-products of normal cellular processes and the body has effective defence mechanisms to handle them. However, an overabundance of free radicals can damage body molecules including DNA. Antioxidants include beta-carotene, vitamins A., C., and E., lycopene, flavonoids and other agents.

*Healthy dietary and eating habits.* Schools and canteen meals, which are becoming popular again, are the best settings for creating daily nutritional rhythms, and offering information on the energy content and quality components of various meals as well as of teaching meal planning skills. The other half of the energy balance involves a way of life that includes exercise, and setting down the prerequisites for physical activity are just as important as nutrition itself among people of all ages in all walks of life.

## 3.1.4. The role of infections in the incidence of cancer

According to European Cancer Code data (2003), 10 percent of cancers in the European Union are the outcome of virus, bacterial, or parasite infections. Cancers triggered by infections include cervical, liver, gastric and certain haematological cancer.

Human papilloma virus infection plays a significant role in the development of cervical cancer. Hepatitis B and C viruses can cause liver cancer. The presence of a Helicobacter pylori infection increases the risk of a gastric tumour by sixfold. The Epstein-Barr virus (EBV) and HIV infections trigger lymphoid cancer while the latter also promotes Kaposi's sarcoma.

Question: who is responsible for a health damaging lifestyle?

Part of the responsibility rests with the individual since lifestyle is "a set of personal decisions impacting health, over which the individual has control to more or less of an extent." Over and above individual responsibility, we need to ask about the cause of the high frequency of tobacco smoking, alcohol consumption and unhealthy nutrition. Regional epidemiological differences suggest that the cultural environment and socio-economic and political conditions also influence the development of cancer. In a stress-filled day-to-day life, the most easily accessible stress-reducing mechanisms, the ones causing momentary pleasure are unhealthy: tobacco smoking and excessive eating and drinking.

Society is amazingly tolerant of these self-damaging forms of behaviour.

For this reason, attaining a better quality of life is an urgent societal task.

## 3.2 Secondary prevention

The goal of secondary prevention is to recognize cancer and pre-cancerous states that show no signs or symptoms, to prevent later, serious consequences. The method is screening.

The clinical phase of the illness begins when signs and symptoms appear. The preclinical phase of the disease covers the period from the beginning in the biological sense until the appearance of symptoms. The goal of screening is to discover the disease in the initial phase.

A negative screening result lowers the probability of a malignant tumour to minimum, while a positive screening result means that there is a high probability that such a tumour exists. It gives the patient a chance to seek medical advice in an early, symptom-free phase of the disease. The goal of screening is to reduce mortality due to certain cancer types. Screening programmes are judged by their sensitivity and specificity, when determining whether they are a suitable tumour gauge.

A method is sensitive if it identifies cancer as cancer, and specific if it only identifies cancer as cancer.

As a result of implementing screening programmes

- a) the number of new patients diagnosed per calendar year (incidence) will increase,
- *b)* the number of cancer diagnosed in the early clinical phase will grow and survival time (the time between diagnosis and death) will lengthen,
- c) the number of deaths due to cancer (mortality) will decrease, and
- d) quality of life indices will improve.

## 3.2.1. Screening in the healthcare system

In healthcare practice, we distinguish between organized mass and ad hoc screenings. In organized mass screenings, the methods used must already have been proven effective in large groups of average-risk people. The only acceptable evidence of effectiveness is a significant decline in mortality from the disease being screened for in the community being screened, a result that can be attributed to the screening. Cervical, breast, and colorectal cancer screening meet these criteria. The other tests that are suitable for early diagnosis of diseases before there are any signs or symptoms, but that are not efficient and must be carried out on an ad-hoc basis, in the course of doctor-patient encounters, in the spirit of doctors' oncological vigilance.

#### Organized mass screenings

Performed within the framework of the healthcare system, and financed from the public purse organised mass screening is a public health action

- embracing population groups considered at risk because of age,
- using personal invitations and the follow-up of targeted persons,
- performed as often as is professionally justified,
- and organized, coordinated, and quality-controlled by the National Public Health and Medical Officers' Service (NPHMOS).

*Breast screening:* Breast screening is performed bi-annually for women aged 45-65, and consists of a mammogram and a physical examination of the breast. Since 2002 a sufficient number of — about 40 — screening facilities that cover the entire country geographically have been in operation. They have both a diagnostic and a sufficient therapeutic referral capacity. The goal is to evolve a system able to screen 80 percent of the women in the above age group on a regular basis. About 43 percent of the women invited to the last screening (in 2002-2003) on nationwide scale appeared for the tests. Mobile screening buses operating as part of the public health programme help to make the screenings more accessible to the public.

*Cervical screening:* For several decades, Hungarian tradition has been to screen the 25-65year-old female population once, and if the result is negative, to invite them to return every three years for a complete gynaecological examination which must include a cytological test (Pap smear). We have a sufficient number of cytological laboratories working on a sufficiently high level to do this. The role of the healthcare system is to introduce a mobile specialized medical service to make the screening accessible to all people who have not taken advantage of the screening opportunity in past decades – particularly people living in the rural areas. Inclusion of family practitioners in the effort and appropriate communication is resulting in an increase in the number of persons screened. The task of coming years – following successes in other countries – will be to include trained allied health personnel (midwives, health visitors) in taking the smears.

*Colorectal screening*: Women and men of age 50-70 are targeted for this screening. The test is performed every two years and seeks to determine if there is any hidden intestinal bleeding, through the immunochemical analysis of faeces. Once model experiments are concluded and the data is processed, the screening can be expanded gradually on broader scale. It will be necessary to develop endoscopy equipment stock in Hungary.

## Ad hoc screenings

*Oral cavity screening*: Given the dramatic increase in mortality due to cancers of the oral cavity, this is an urgent task. A priority task of family practitioners and occupational health physicians, as well as dental and oral cavity specialists is to look at the oral cavity and conduct palpation tests, and to refer cases screened out to the appropriate specialist.

*Prostate gland screening:* Demonstrating the presence of prostate-specific antigen (PSA) and a palpation examination of the prostate gland through the rectum is an appropriate manner of screening for prostate cancer. At present, there is no internationally recognized evidence-based procedure for screening for prostate cancer that can be applied on large scale with a high level of reliability. The examinations used are only informative and when evaluating results individual risk factors, symptoms, and other examinations also have to be considered. For this reason, we do not at this time recommend prostate screening as a general public health screening test.

Considering the large number of prostate cancer, however, we must maintain a wide-scale information campaign among the male population that covers the hazards of these tumours, and the early-warning signs, symptoms, and body changes with which they should immediately seek medical attention. Early recognition and close monitoring of minimal changes will make timely intervention possible, leading to full recovery.

*Skin screening:* International literature warns that the incidence of skin cancer is rising continuously. Two-thirds of skin cancer are associated with the damaging affects of sunrays. Skin cancers are easy to notice, but early recognition is hampered by the fact that they do not look like malignant skin changes and people do not suspect that they are cancerous. Melanoma is one of the most malignant tumours. Although melanoma accounts for only 4 percent of skin cancer, they cause the vast majority of mortality due to skin cancer.

To achieve the earliest possible diagnosis of skin cancer, symptom-free persons aged 20-40 years should be screened by a dermatologist every three years and people over the age of 40 years should be screened annually.

Self-examination of the skin to notice any new growths and other changes is recommended.

*Fluorography:* While once tuberculosis was the most feared respiratory disorder, today its place has been taken by lung cancer. Throughout the world – including Hungary – lung cancer is the number one cause of cancer death. As of 2003, it also became the number one cancer killer among women. The seriousness of the problem is also shown by the fact that morbidity and mortality rates are about equal. This requires urgent action.

Most cases of lung cancer are diagnosed by fluorography. About 20 percent of the cases discovered are still operable, and that does increase survival time. However, that "achievement" is not reflected in any decline in mortality.

The existing pulmonary continuing care facilities, including specialists, middle health personnel, and equipment, need to be upgraded to handle lung cancer screening and to deliver continuing follow-up care for patients. Turned into "health centres" they would be able to deliver a broad range of activities promoting prevention and early diagnosis.

Testicle screening: Recommended annually, starting at the age of 18 years.

Secondary prevention in paediatric oncology

It is mandatory to perform paediatric examinations in neonates, infants, and children (as opposed to adulthood) and these check-ups should make early diagnosis possible.

## **4. CANCER PATIENT CARE**

Cancer diagnostics and the methodology of therapy and rehabilitation have expanded to an unbelievable extent over the past decade. In a changed social environment, the public expects complex cancer care services from highly qualified professionals. In Hungary, cancer morbidity is on the rise, and successful treatment is the result of a long-lasting process.

From the point of view of equity, there is discrimination in the other related professions, charged with caring for cancer patients, regarding both personal and objective conditions and cooperation among the professions.

## 4.1 Cancer diagnosis

Early diagnosis of cancer is of key importance because the time of diagnosis determines primary therapeutic decisions which in turn determine the survival chances of a cancer patient.

Modern cancer diagnostics depends on (1) imaging processes, (2) laboratory tests, and (3) pathology investigations (biopsies). Effective and up-to-date cancer therapy and diagnostics are based on close cooperation between specialists (a cancer care team), and on organized consultations, in other words, on multidisciplinary communications.

Organized consultations offer opportunities to move beyond routine protocols and discuss individual diagnoses and treatment regimes.

The above diagnostic procedures must guarantee the fastest possible transfer of findings to the patient and the attending physician. In Hungary, the instruments used for all three diagnostic activities are obsolete and there is a serious shortage of specialists (also see telemedicine).

## 4.1.1. Imaging procedures

Radiological and isotope diagnostics are of strategic importance to therapy and have undergone tremendous technological development in the past quarter century. By today, this development is placing more and more demand on both investors and users. The imaging methods of the past century were based on discoveries in physics and offered anatomical information. Current imaging focuses on visualising functional, molecular conditions, identifying and monitoring disease-related phenomena.

*Imaging methods:* Digital cross-sectional imaging methods, including computer tomography (CT), ultrasound, magnetic resonance imaging (MRI), and positron emission tomography (PET), offer tremendous opportunities for the early diagnosis and pinpointing of disorders.

Imaging procedures play roles in every step of the oncology examination algorithm. They are used to show the presence of cancer, the stage they are in, to measure the effectiveness of treatment, to monitor the patient, to achieve early discovery of recurrence, and to determine changes in stage.

A carefully chosen radio-diagnostic procedure can make a huge contribution towards selecting an appropriate treatment which in turn can increase the survival chances of cancer patients.

To be able to evaluate an examination, one needs not only an appropriate technology for one must also have the procedures that conform to the protocol.

## 4.1.2. Laboratory tests – tumour markers

The term tumour marker is used in international literature to mean an organ-specific material of which an elevated amount is present in body fluids, whereas in similar body fluids it would appear in only low concentrations if at all in a healthy person or a person who did not have a tumour.

Even though these markers are generally not specific, they have become an important tool in the early recognition that a tumour is present or has recurred.

In Hungary, tumour markers are not tested to the extent that international expectations would warrant. In the European Union countries, they are used to a steadily growing degree, In Austria about 2.5 million such tests were performed in 2000, and in Belgium the rate was about 3 million. In Hungary about 300,000 such tests were performed although the real need is about the same as in the other two countries mentioned.

One reason why the tests are not performed is that cancer care in Hungary does not evaluate the information gleaned from tumour marker tests in a realistic or uniform manner.

## 4.1.3. Pathological diagnostics

Pathological tests play an important role in every single step from screening to the treatment of cancer patients, since without a pathological diagnosis, no tumour treatment regimen can be designed. The personal and objective conditions for these examinations need to be guaranteed in all phases of the healthcare system.

Modern pathological diagnostics includes microscopic cellular and tissue diagnostics, which is the only way of demonstrating the presence of cancer and precancerous conditions. These tests play an important role in determining how widespread the tumours are and offer information on treatment options. This makes them essential in choosing a treatment plan and in monitoring the patient (prognostic pathology). They contribute to determining individual sensitivity to treatment, as well as to defining the molecular targets at which the drugs selected for treatment are to be aimed (molecular pathology).

Pathological diagnostics includes the performing of post mortem examinations and conducting the related clinical pathological evaluations. This is one of the most important quality control activities in cancer patient care.

Modern pathological diagnostics require significant human resources. We must provide professionals (specialist physicians, non-specialist physicians, and allied health personnel) to reduce the staff shortages.

#### **4.2 Therapy: complex cancer treatment**

In past decades, two types of care have evolved in treating cancer patients in Hungary. On the one hand, oncology centres have been brought about as separate facilities or as facilities operating in hospitals, which offer up-to-date diagnostics and can provide many of the conditions needed for complex cancer treatment. In other hospitals, however, cancer patients are treated by various medical disciplines and that treatment is based on principles that are by far not uniform on state-of-the-art.

In order to see to it that uniform principles of treatment are applied, on December 1, 2005, the facilities in which cancer patients are to receive up-to-date care in accordance with treatment and financing protocols that have already been defined were named. A decision was also taken that certain types of tumours (such as paediatric cancers, haematological malignancies, lung cancer, brain tumours, and eye tumours) were not to be treated in the oncology centres but in separate units of specialist facilities, partly because of their specifics and partly because of Hungarian practices. Diagnostical and treatment principles, as well as demands for development and upgrading, are of course just as valid for the facilities providing care for these types of cancer.

A multidisciplinary strategy is needed for the modern treatment of malignancies. The treatment regimen includes surgery, radiation therapy, pharmaceutical therapy, rehabilitation, and care of terminally ill patients. The treatment protocol must include psychological assistance and modern pain control.

### 4.2.1. Surgery

Today, in about three-quarters of cases, surgery (general surgery, chest surgery, urological surgery, gynaecological surgery, head-neck surgery, orthopaedic surgery, neurosurgery, ophthalmic surgery, etc.), either of itself or in combination with other forms to treatment, can provide benefits to patient: it can offer recovery or palliative care, fundamentally influencing not only lifespan but quality of life, too. Radical surgery, which is often disfiguring and requires a high level of tolerance on the part of the patient did not necessarily result in longer survival rates or better quality of life, so today the important thing is choosing surgical treatment that is commensurate with the stage of the illness. Today, appropriate radiation therapy and pharmaceutical treatment have grown in importance as have primary tumour surgery methods that allow functions to be retained and do not ignore aesthetic considerations. In addition, there are now increased possibilities of surgically removing distant metastases.

There are numerous conditions that must be met for surgical treatment to be successful. It is important that the tumour be recognized in an early stage, which screenings are intended to facilitate. It is essential that the stage be measured accurately and quickly prior to the surgery, in keeping with the type of tumour diagnosed and its specifics. (In addition to conventional basic tests, today it is expected that testing include CT, MRI, and endoscopic imaging, targeted biopsy, marker testing, and if necessary, PET scans.) Actual surgery should

be based on test results. Today's tumour surgery may require special conditions (such as intraoperational biopsy and cytological analysis, imaging, modern prosthetics, plastic surgery tools, radio-frequency tools, etc.).

The basics for reconstructive surgery following mutilating surgery must be established so that it becomes part of tumour surgery, performed in the oncology centres.

## 4.2.2. Radiation therapy

Radiation therapy plays a highly significant role in the complex treatment of malignancies. Radiation therapy is used on about half of all patients with malignant tumours. The number of patients who can be successfully treated with radiation therapy has increased and correspondingly, the number of patients treated in this way has also expanded.

According to the latest reliable surveys from Western and Central Europe, Hungary has the poorest infrastructure in the European Union and puts the heaviest workload on its personnel.

*High-energy radiation equipment:* International recommendations call for 50 highenergy radiation equipment for 10 million people. Hungary currently has 12 radiation therapy sites, 23 linear accelerators and 10 telecobalt machines that may be used principally for palliative care only.

*Brachytherapy equipment:* State-of-the-art high dose rate remote afterloading equipment operates in nearly all radiation therapy facilities. Iodine-125 brachytherapy seeds implanted in prostate cancer patients are not accessible in Hungary at the moment, but are needed.

About 15 percent of jobs for radiation oncologists are vacant. As demands increase there is more and more need promote the training of radiation oncologists, physicists, radiation therapists and specialist technologists and to set up radiation biology departments.

## 4.2.3. Pharmacological treatment

One important way of treating malignancies within the framework of complex cancer care is pharmacological treatment, which may be cytostatic, hormonal and biological treatment, or a combination of the above. When the disease is advanced, either used alone or in combination with other treatment modalities, it can lead to the recovery of 15 percent of patients, and the life expectancy for many more can be prolonged while providing a satisfactory quality of life.

By international definition, clinical oncology is a separate professional area that requires special training and experience. The discipline requires not only clinical oncologists, but nurses with appropriate experience, and a satisfactory environment as well.

Most departments that offer pharmacological treatment do not have modern equipment to protect staff. Clinical oncology requires specialist physicians as well as a satisfactory professional environment, equipment, nurses with appropriate experience and other professional staff. An essential condition for a Hungarian oncology network to operate in a modern and efficient manner is access to tumour-inhibiting drugs and other special pharmaceuticals of satisfactory quality, prepared under satisfactory conditions. It must be possible to assure and guarantee that infusions of cytostatic mixes are handled under controlled conditions, and that personal and objective conditions are adhered to when preparing them. The minimum professional conditions published in 2004 serve as the guidelines for this, but in many facilities, these professional conditions are not guaranteed. In Hungary, opportunities for the pharmacological treatment of cancer are up-to-date. The treatment is cost-intensive and international forecasts suggest that it will become significantly more expensive as time goes on.

## 4.2.4. Biological treatment

Biological treatment is a special form of therapy, in which natural materials that occur in a living organism and medications made from them are used to combat cancer. Most biological treatments are part of experimental tumour treatment, but a number of applications have already been introduced to clinical practice.

The main components of biological treatment are as follows:

## Monoclonal antibodies

Most therapies based on monoclonal antibodies are in the clinical trial phase but some are already recommended for chemotherapy-resistant cases, or as adjuvant therapy.

## Growth factors and cytokines

Growth factors are predominantly natural materials that affect blood formation. In tumour therapy, they are used to reduce the side effects of pharmacological therapy.

Some cytokines are used in adjuvant therapy when treating melanomas, myelomas, and kidney tumours.

## Immunization against cancer

Immunization against cancer is performed principally to treat full-fledged cancer although it might also be used in tumour prevention. The immunization procedures used most often that deserve mention are antigen, DNA-based, and anti-idiotype antibodies as well as complete cellular and dendrite-based immunization procedures.

## Anti angiogenesis therapy

As we have learned more about the nature of revascularization, it has become possible to prevent the formation of the new blood vessels needed to supply blood to cancer.

## Genetic therapy

This is the most rapidly advancing area, where on long term a significant improvement in the success of tumour treatment is expected, thanks to new approaches.

## Tumour growth inhibition

Tyrosine kinases play a significant role in the regulation of cell growth and division. It is now possible to ascertain the types of tyrosine kinases triggering specific growth on genetic or protein level. At the same time, molecules able to inhibit the operation of tyrosine kinases have now been discovered.

### BCG therapy

This immune modulation procedure is used to inhibit the recurrence of bladder cancer.

Biological tumour treatment procedures are an old-new trend that offer results in conventional therapy-resistant cases thanks to new research achievements. They also offer treatment options more favourable from the point of view of side effects. However, significant advances still have to be made here. The current infrastructure would be able to meet demands with minimal investment.

## 4.2.5. The complex rehabilitation of cancer patients

In Hungary, the incidence of cancer has been rising steadily. Treatment is a long-lasting chronic process, and the physical burden of treatment makes it harder for patients to maintain their psychosocial balance. The world changes for a tumour patient. Working ability is reduced, the role in the family is altered, physical and emotional strength is taxed, and financial status and quality of life are at risk.

The medical, family, and social rehabilitation of a tumour patient begins when the diagnosis is confirmed. Rehabilitation is an organic combination of managing physical and emotional issues.

Physical rehabilitation is focused on preventing or terminating the anatomical and functional damage caused when treating the tumour through surgery in which functioning is retained, surgical reconstruction, or symptom alleviation treatment. The involvement of physical therapists, nurses with experience in managing stomas, and speech therapists is important.

Among cancer patients, emotional assistance is inseparable from physical treatment. The emotional state of the patient is most strongly influenced by the family and the immediate environment, so it is important that people surrounding the patient be prepared for what the treatment entails. The psychological training of healthcare personnel is very important and in given case, a psychologist or even a psychiatrist may be necessary for crisis intervention, individual therapy, group therapy, cognitive-behavioural therapy, or movement and relaxation therapy.

Physical and emotional rehabilitation are already available in county-level oncology centres.

The most important factor in managing symptoms is pain relief, preferably with a satisfactory combination, dosage and timing of medications. In about one-fifth of cases, the pain cannot be mitigated with medication and invasive pain relief must be employed.

There are many things that must be done to relieve the symptoms of cancer patients. Palliative care must be employed to relieve the overwhelming feelings of weakness, lack of appetite, itching, diarrhoea, difficulty in breathing, anaemia, etc. of these patients to improve quality of life, which is one of the defining pillars of today's oncological approach.

A complex rehabilitation system has multiple and diverse tasks managed by various teams:

*Psycho-oncological team:* in addition to physical problems, a tumour patient has psychological problems to overcome. It is important to resolve the psychological problem of a patient who needs such assistance. During and after treatment, the task of the team is to care for patients and help the re-adjustment to healthy society. They provide individual and group

therapy, life-management counselling, they lead support groups, and they organize creative workshops.

*Chaplaincy services team:* Among people with serious illnesses, religious faith often is facilitation in acceptance of a situation. The chaplaincy services team offers these patients support to keep them going.

*Social team:* In Hungary, often cancer patients find themselves in socially untenable situations as soon as their diagnosis is learned by others, or during the course of treatment. They lose their jobs, and find themselves in dire financial circumstances. The task of this team is to provide information on available social services and to seek new job opportunities for them.

*Nutrition team:* 50 percent of cancer patients are undernourished when they are diagnosed, and this becomes even more acute during the course of treatment. The role of the team is to offer dietetic counselling to patients, and if necessary, to manage feeding at home or on an outpatient basis.

*Information supply team:* There is a great deal of irrationality and many mistaken ideas about cancer patients in Hungary, and about the extent to which they can recover. This is one reason it is important to be as professional as possible in offering information on screenings. This team offers information brochures and edits a website called 'Firebird' to provide information to patients. This team is designated to operate the "cancer line" telephone network along with the Hungarian Cancer Control League.

*Education team*: Working with volunteers is necessary, similarly to foreign practices. The role of this team is to train a network of lay volunteers for patient advocacy organizations and to set the tasks they manage.

Alternative therapeutic procedures advisory service: There are increasing expectations in our society regarding exploitation of the opportunities inherent in working with complementary medical practitioners. There is a particularly strong demand among persons with cancer who often feel that their situations are hopeless. Operating a counselling service would protect patients and help them access various effective alternative healing procedures.

## **5. HOSPICE (PALLIATIVE CARE)**

This is a form of healthcare focused on patients who cannot recover – it is primarily for cancer patients who are terminally ill and in the final stages of the disease – and it offers them alleviation of pain and other torturous symptoms, an improvement in quality of life, and support for family members and the bereaved through a multidisciplinary team of carers.

Forms of hospice care

#### I. Mobile team offering palliative care

This involves specialist care to patients who are hospitalized, who have been placed in another long-term inpatient facility, or are living at home. The goal is to offer specialist palliative care to terminally ill patients treated in different facilities and departments.

Tasks:

- to offer professional assistance to terminally ill patients, principally cancer patients, and to their families through a specially trained interdisciplinary team;
- to offer professional consultative assistance to staff of hospitals and domiciliary skilled nursing care services.

The mobile team must have a backup institution offering professional hospital nursing and/or skilled nursing care at home.

#### II. Hospice care provided in the patient's home

This is skilled care offered in the home and aimed at helping the patient and the patient's environment to adhere to the treatment regimen set up by the physician, to initiate changes in it when necessary, and to provide professional caring and living assistance to the patient.

Home hospice care is available only for terminally ill patients. Home hospice care only may be provided if the provider of skilled nursing care at home can meet the minimum personnel and equipment conditions required of hospice care.

#### III. Hospice and palliative care hospital ward

This is a separate palliative care department or unit of an inpatient service provider.

The condition for its operation is that it must have a supplementary home-hospice care unit.

The concepts of *palliative care, hospice, and home care* are new in Hungary, and have not evolved to the extent they deserve, given their value. Most efforts have been the result of NGO or faith-based initiatives, which have been able to offer 24-hour continuous palliative care that improves quality of life for terminally ill patients in the home or in a homelike environment. It is a team effort involving family practitioners, oncologists, qualified nurses, physical therapists, psychologists, chaplains, social workers and volunteers, working together as individual cases warrant their services.

Each year over 33,000 Hungarians die of cancer but only about 2,000-2,500 receive hospice care. Hospice offers full-scale care to patients who will not recover – principally to patients in the terminal phase of cancer – where the main goals are to alleviate pain, treat symptoms, and resolve psychological and spiritual problems. The goal is to offer the highest possible quality of life to the patient and to patient's family. It is unique in that a specially trained interdisciplinary team offers the care.

Hospice has existed in Hungary since 1991. There is a minister's decree that regulates the personnel and equipment conditions for hospice and home care.

At present, there are 11 inpatient hospice facilities with 143 beds, 29 home hospice care groups, two day-sanatoria, and 6 nursing homes and senior citizen homes where hospice care is provided on 46 beds. In addition, there are four mobile hospice teams (hospital support groups). In other words, there are a total of 52 organizations with 189 beds (including the 29 organizations participating in a model programme organized by the National Health Insurance Fund [OEP] which covers 8 inpatient wards and 21 home hospice teams).

According to data of the World Health Organisation a minimum of 5 palliative beds are needed per 100,000 population. This means that Hungary would need a minimum of 500 hospice/palliative beds.

## 6. THE ORGANIZATION OF CANCER CARE

The goal of caring for patients with cancer is to successfully treat the disease and achieve the physical and emotional rehabilitation of the patient. The condition for meeting that goal is maintaining an effective care network with appropriate target programmes, establishing the conditions for needed development, and providing training and continuing education for all persons involved in treating cancer patients.

## 6.1 The current status of cancer care

According to specialised care data, all healthcare service providers throughout the country are involved with cancer treatment. Since the various institutions offering cancer treatment differ in their levels of professional expertise and capacities, the level of care received by cancer patients differs sharply from one locality and type of facility to the next.

The fluctuating levels of regional cancer care are the result of one or more of the following shortcomings:

- an absence of oncology teams leading to mosaic-like uncoordinated treatment,
- a lack of radiation therapy equipment,
- limited access to reconstructive surgery,
- a lack of rehabilitation opportunities,
- too few pain clinics,
- insufficient hospice facilities,
- a lack of reliable register of continuous care.

The network of continuous cancer care evolved in the early 1950s using central government resources and operating under central management. At present, there are 86 oncological continuous care facilities located through the country, covering it well. However, most of these facilities are not equipped with the modern tools and equipment needed to screen for, properly diagnose, treat and offer rehabilitation for all types of cancer. For this reason, the tasks they handle need to be reorganized.

At this time, there are 1,700 oncology beds being used to treat cancer patients with pharmacological and radiation therapy, and to care for chronic patients. This number of beds is not enough to manage the tasks listed above in an appropriate manner. In addition, when speaking of the number of beds, it is vital that a sharp distinction be made among the various therapeutic modalities and the different services required. Unless the various activities are kept separate, it will not be possible to appropriately manage either the special tasks or the nursing tasks.

## 6.2 The organizational structure of cancer care

At present, the cancer care facilities are organized and operate as *hierarchic networks*. The tasks are managed by the network of family practitioners, the oncology departments of the municipal/county/Budapest municipal hospitals, the clinical oncology departments of universities, and on the top of the nationwide network, the National Institute of Oncology.

## The role of primary health care is to

- educate for healthy way of life (working in cooperation with the schools)

- regularly monitor individual risks, and, working in cooperation with National Public Health and Medical Officers' Service, to organize screenings and motivate patients to participate in them,

- perform the examinations aimed at early diagnosis within their own sphere of professional competence (such as oral cavity, skin screening, etc.),

- encourage the patient to visit a specialist diagnostic centre, when a tumour is suspected,

- participate in the home care of cancer patients,

- initiate the rehabilitation and promote the readjustment of recovered patients to the world of work.

The current task of the oncology continuing care facilities is to

- organize a professional relationship between the family practitioners, the occupational health service, National Public Health and Medical Officers' Service, and specialist cancer care services,
- participate in primary prevention, ad hoc screenings, rehabilitation, and palliative care.

County and Budapest metropolitan clinical oncology departments assume *the role of county level cancer care centres*, which professionally integrate the cancer care facilities in their regions and the hospital and clinic units that handle all cancer care activities. Their job is to:

- make certain that all persons sent to them because a tumour is suspected receive a complete oncology work up,

- organize and operate multidisciplinary oncology teams,
- offer care in keeping with oncology protocols,
- offer professional supervision and control to the cancer care facilities in their regions,
- provide oncology consultations when requested to do so,
- offer professional supervision and control to the cancer care facilities in their regions,
- coordinate all tumour care activities underway in the county,
- organize the sequence of visits a patient must make to receive treatment,
- offer consultative assistance to family practitioners.

*Regional cancer care centres* need to be established to coordinate the cancer care of larger populations (2 to 2.5 million people), in conformity with European Union regions. It is essential that each facility must be able to offer satisfactory radiation therapy and have the capacity to treat all patients requiring it. Their role is to:

- provide the full range of cancer diagnostics,
- organize and operate oncology teams,
- offer the full range of complex oncology treatments including radiation therapy,

- test new oncology protocols and introduce them in accordance with the rules of the profession,

- participate in undergraduate and graduate education,
- participate in oncology research.

## The tasks of the National Institute of Oncology:

– to coordinate Hungarian cancer care, the regional and county level oncology centres, and to offer methodology assistance to the activity of the cancer care networks, to work together with the Professional College to prepare professional guidelines and protocols, to introduce same and to ensure equal access to a uniform level of professional care, - on request, to offer professional opinions of how justified it is for Hungarian citizens to seek treatment in other countries,

- on request to participate in Hungarian oncology research and international cooperation programmes,

- to promote the Hungarian introduction of the latest achievements in complex oncology treatment.

### 6.3 Paediatric cancer care

The regional centres of the Hungarian paediatric cancer care network are located in the seven planning and strategic regions of the country that were evolved after the country acceded to the European Union.

The tasks of the paediatric cancer care system

The defining majority of paediatric cancer treatment (nearly 90 percent) is made up of intensive chemotherapy, 30 percent involves surgery, and 20 percent consists of radiation therapy. Active combined therapy, especially long-lasting intensive pharmacological therapy and treatment to overcome the acute and chronic complications and side effects of this therapy, requires repeated inpatient hospital care of longer or shorter duration. Often the need for acute and many times for intensive nursing care becomes combined with phases in which chronic care is also required. The age specifics of the patients (infants to adolescents) make the levels of necessary care even more complex. In addition to overcoming the disease, the physical and emotional development of the children must be assured to the extent that this is possible. Maintaining the inseparable bond between mother and child, and retaining the normal functions of a child's link to the family require special attention. Once active treatment is concluded, the child will require long-term follow-up until adulthood. In paediatric oncology, the number of lives saved per capita is high, and the quality of those lives is of primary importance.

This goes to show that there is a significant difference between paediatric cancer care versus adult cancer care.

Paediatric cancer care centres handle diverse, complex, and unique tasks, and for that reason, the paediatric cancer care wards offer services that go well beyond general paediatric care, offering specific oncological haematology treatment with a multidisciplinary team in the background.

#### Current activity of the paediatric cancer care network

Paediatric oncology centres provide multidisciplinary care for all types of childhood cancers – using internationally accepted diagnostic and therapeutic procedures that rest on uniform principles – within the institution or in collaboration with other institutions.

The pharmaceuticals needed to treat paediatric cancers are available. With Hungarian paediatric cancer care organized in this way, Hungarian treatment successes are just barely behind or even on the same levels as in advanced countries.

Paediatric oncology rehabilitation operations are focused on maintaining motivation. They offer incentives to creativity and monitor age specifics in promoting personality development. The work begins in the hospital, at the same time the diagnosis is set up.

The methods include offering crisis intervention to parents, and organizing psychotherapy, play therapy, and occupational therapy for children, providing schooling while

in the hospital, establishing contacts with preschool children and schoolchildren, giving assistance to families including family counselling, making careful emotional preparation for surgery and/or transplantation, and offering full support to terminally ill children, and their families.

Rehabilitation procedures employed outside the hospital include family visits and personal meetings with responsible healthcare forums to lobby for the patient and family. In cases when the child dies, they involve the organization of emotional assistance to the family. Rehabilitation helps older children in continuing their educations or choosing careers, and it also handles actions such as organizing regular summer holidays and camps for children with malignancies

Psychologists, teachers, physical therapists, and social workers help the centres with their work.

There are foundations in the agglomerations of all centres that work to support oncology patient care. The centres have means of transporting mothers or other ways of providing accommodations for parents, which assures that the parents may remain with their children and may participate in helping their children recover during the period of hospital treatment.

## 6.4 The IT status of cancer care services

In the Hungarian facilities in which cancer patients are treated, it will be necessary to adapt and introduce an information technology infrastructure that is adjusted to and coordinated with the level of care quality, and that meshes with the specifics and demands of organizationally combined operation. Initially, this will mean better and different use of existing features, to meet the new way of thinking and new demands. However, it will be essential to comprehensively revamp the Hungarian IT systems and upgrade them. Considering the special demands of cancer treatment, it will be necessary to gradually evolve a nationwide integrated information system built of differentiated elements that can be broken down by region, although it must be comprehensive from the professional point of view. This system will have to be able to manage patient data and all necessary and possible information related to patient care.

To this end, Hungary has joined the EUROCHIP project established with funding from Brussels. The goal is to collect and analyze the morbidity and mortality data of the 25 members as well as all data on primary and secondary prevention. It is important that oncology IT meshes with the telemedicine network being established and with the existing Hungarian hospital information technology systems.

## 7. THE ROLE OF RESEARCH & DEVELOPMENT

Success in the effort to combat cancer depends on the outcome of cancer research and the effectiveness of the most important findings when put into practice. Oncology research is based on exposing the basic mechanisms under which tumours begin forming, grow, and proliferate. In recent years, the transfer of research results to oncology practice has accelerated, which is a huge challenge to the profession.

Learning the human genome has opened new perspectives for oncology researchers, but raises the requirement for continuous development and coordination. Thanks to genetic and genomic research, oncology diagnostics and treatment are expected to undergo a radical transformation in the near future. Within its current framework programme, the European Union considers the concept of introducing the genomic and biotechnology arsenal to the effort to control cancer to be a top priority, and it has been providing member countries with significant grants for promising research to augment national cancer research supports. Internationally recognized molecular oncology research has been underway in Hungary for over twenty years. It is absolutely necessary that this research be included as a key component of the National Cancer Control programme, in conformity with international practices, if we are to provide patients with the latest scientifically verified diagnostic and treatment procedures and maintain the international competitiveness of Hungarian cancer research.

- 1. In past years, the results of genetic and genomic research led to revolutionary changes in all aspects of tumour research, and this has resulted in changes in diagnostic and therapeutic protocols. Some of these changes are:
- 2. The results of basic research have become part of diagnostics. Molecular procedures have become a basic pillar of clinical oncology. The role of applied clinical research is to adapt new procedures in the diagnostics and treatment of cancer. The primary goal is to be able to offer individualized tumour therapy and to be able to access the tools and methods needed for that.
- 3. Participation in international research flows under contracts with both the European Union and the United States can lead to new opportunities in Hungarian clinical research.

We must offer support to innovative research and the workshops conducting it, both on Hungarian level and as part of international cooperation projects. Cooperation with industries concerned with diagnostic and therapeutic procedures strongly promotes the activeness of Hungarian oncology research. Participation in clinical drug trials conducted within international cooperation processes is particularly important.

# 8. COORDINATING EUROPEAN-LEVEL CANCER CARE, AND INTERNATIONAL RELATIONS

When Hungary joined the European Union, it became important for it to introduce the programmes used successfully to combat cancer within the EU to Hungary, too. The significant elements of the European cancer control programme are included in the European Code Against Cancer. The third edition of the Code Against Cancer was published in 2003, and Hungary shared in designing it. Hungary must participate just as actively in all European or global programmes that coordinate oncology activity (such as the Organization of European Cancer Institutes, WHO's Cancer Research Agency in Lyon, etc.)

The Organization of European Cancer Institutes (OECI) is a network of 80 cancer centres in 29 European countries and it is still growing. The organization coordinates the prevention, patient treatment, research, development, care and educational efforts of the professional cancer centres. Its most important goals are to reduce overall cancer mortality, to improve quality of life and the standard of care for cancer patients and to promote the adaptation of research results to clinical oncology practice. Earlier, the set of criteria that defined the European Cancer Centres was not defined, and there are still major differences between the institutions of the various countries. OECI envisages the coordination and levelling out of disparities in three steps: (1) defining the quality level of cancer treatment, (2) establishing a common accreditation system of cancer centres in Europe, and (3) elaborating a common European curriculum for oncology education. The professionals working together in the specific working groups within the framework of OECI have designed and adopted common European cancer therapy protocols, have defined the manner of accrediting cancer treatment facilities, and have elaborated a European system for training oncology specialists.

The other area in which Hungary is participating in the implementation of European goals concerns close cooperation with WHO's Cancer Research Agency in Lyon (I.A.R.C.) The Cancer Agency is charged with coordinating European projects and those of other continents to control cancer. It endeavours to achieve a fully circumspect and comprehensive approach that includes all possible aspects of the projects. Hungary participates in the scientific council.

Another major area of European cooperation involves efforts to renew national cancer control programmes under the coordination of the WHO Headquarters in Geneva. Participating countries, including Hungary, were chosen on the basis of the work they have already done in the field.

The cancer researchers at the various schools of medicine have established an extensive network of contacts in Europe and overseas, making future cooperation a certainty.

We are participating in the continuing education and scientific activity of ESMO (the European Society of Medical Oncologists), which offers accredited training in Europe.

One unique mode of Hungary's healthcare cooperation, one that is growing in importance, was initiated by United States Ambassador to Hungary Nancy Goodman Brinker. She brought new methods to control breast cancer to the country by activating NGOs. The current U. S. Ambassador to Hungary has recommended a (prostate) screening programme to protect male health.

In January 2005, the Hungarian Minister of Health and the United States Secretary of Health and Human Services signed a memorandum of understanding, which is one part of the effort to cooperate in research with the leading professional institutions of the world including the International Cancer Institute.

The breast cancer programme (involving a traditional 'Annual Chain Bridge Walk', a commemorative stamp to combat breast cancer, and a Central and Eastern European breast cancer symposium held in Budapest in March 2006) is of defining importance in the effort to maintain health, and prevent and combat cancer. These initiatives promote ways of raising society's awareness in fighting other types of cancer.

The International BFM Study Group plays an outstanding role in designing therapies for paediatric leukaemia, in continuously advancing those therapies, and in offering education programmes targeting prevention. It originally began as a cooperative venture inside Germany (initiated by clinics in Berlin, Frankfurt, and Muenster), an effort since joined by paediatric oncology teams and clinics not only in the dominant countries of Europe but also in the United States and the Far East. All therapy protocols used in Hungary to treat paediatric leukaemia and lymphoma come from the BFM.

The paediatric cancer care network cooperates on an institutional level with the European countries, while the various centres maintain individual bilateral ties including participation in scientific cooperation projects supported by the European Union. They have also established close professional contacts with several research facilities in the United States. A cooperation effort is underway with Texas Children's Hospital in research to demonstrate the molecular genetic prognostic factors for paediatric solid tumours (particularly focusing on brain tumours). Most paediatric oncology centres have international scientific relations.

# 9. PERSONNEL: EDUCATING PERSONNEL WHO WORK IN CANCER CARE

The rapid and extensive advance of science and the development of applied technologies in oncology require continuous updates in the information levels of the specialist professionals who are active in the practical aspects of the field.

## 9.1. Undergraduate and postgraduate medical education

A sufficient number of appropriately trained specialist physicians are fundamental to cancer treatment. The schools of medicine and the National Institute of Oncology play the defining role in training specialist physicians. (Advancing the institutions that offer education and significantly improving their competitiveness in conformity with one of the central targets of the European Union are very important tasks.)

Level one is made up of undergraduate education, where tumour-related issues appear in the curriculum by disciplines and in the form of courses. It would be a significant step forward if the four universities with schools of medicine were to better coordinate their oncology education and design a joint core curriculum. Training in oncology should also be prominent in dentistry and pharmacology teaching.

Level two is postgraduate education, part of which is specialist training, while the other part involves PhD studies. In the current system, specialisation in clinical oncology is possible as a second board examination (subspecialty). However, the rise in the number of cancer makes it essential that training in clinical oncology become part of undergraduate studies given the complex patient care system. This would make it possible for a sufficient number of young doctors to consider oncology a life's calling and become committed to treating cancer patients. This would alter the current sorry state in which over half of cancer patients are treated by doctors who are not qualified oncologists. Since nearly half of the qualified oncologists do not work in oncology, more doctors should be trained as oncology specialists.

Special emphasis needs to be placed on lifelong learning for specialist physicians.

## 9.2 Training specialists other than doctors

Many tasks in oncology must be performed by specially trained professionals. This is an area where multi level (bachelor + master) education, resting on the Bologna principles, could be applied to higher education. Schools should be reviewed and accredited with this in mind. Unnecessary overlaps could be eliminated and appropriate professional concepts should be applied. It is very important that when the curricula for bachelor's and master's degrees are established, graduates be granted greater autonomy in their authorizations to seek work than they have at present. This would mesh with practice and be more up-to-date than the current system is.

Given the nature of progressive care, the physical and mental care of a tumour patient is quite diverse. In both diagnostics and therapy, one needs technicians, technologists (with special skills), specialist oncology nurses to support clinical work, physical therapists (with special training in rehabilitation), dieticians, psycho-oncologists, and special advisors (for instance, in information transfers and in evolving education teams.)

## 9.2.1. Psychologist training

In Hungary today, fewer than one-third of the oncology departments have psychologists, a rate that does not rise about 50 percent, even in the top-of-the-line oncology centres. Most

of the psychologists they do have, have been trained only in general psychology, and very few are onco-psychologists. Basic training should also include the mental health of hospital workers and the psychological aspects of working with terminal patients. When in training, psychology students should be prepared to help shape appropriate behaviours on a societywide level, to prepare healthcare workers whose jobs are in complex cancer therapy and rehabilitation, to prevent "burnout," and to become an emotional support to patients.

## 9.2.2. Nursing and allied health personnel and specialist technicians

Programmes to qualify workers who provide cancer care and to give them continuing education receive priority support. The goal is to train them to provide nursing and rehabilitation to patients in diagnostics and radiation therapy, and in cancer centres, as well as to assist families, and to offer extension training in these areas, as well as to be able to cooperate with others to promote complex patient care.

The areas of specialization for which training is currently supported are:

- *a)* specialist technician in cytological pre-screening,
- b) specialist technician in histochemistry and immunological histochemistry,
- c) specialist technician in radiological pharmacology,
- d) diagnostic imaging technologist,
- *e*) isotope technician,
- *f*) oncology nurse specialist,
- g) hospice nurse and coordinator.

In addition, it would be important to involve nutritional experts (dieticians) in prevention as well as in rehabilitation.

There are extreme differences in the numbers of specialists available from one region to the next, which deteriorates the feasibility of complex care. Training and human resource programmes need to ensure a sufficient number of professionals to meet growing demands, which also means that all regions should have sufficient staff.

At present, the Institute for Basic and Continuing Education of Health Workers (ETI) organizes basic and continuing education for nursing and allied health personnel and specialist technicians. The Hungarian Nursing Association also participates in providing continuing education to nursing and allied health personnel.

## 9.2.3. Training lay volunteers

Training and preparing the increasing number of lay volunteers who are appearing in growing numbers is the job of the given patient care facility.

## 9.3 Education and continuing education of family practitioners

Given shortcomings in education, similarly to specialists involved with oncology, family practitioners often are not aware of methods for preventing cancer, or of the basic principles of complex therapy and rehabilitation. When the network of family practitioners was established, the tasks of the specialists made the organization of education and continuing education in oncology necessary, and the provision of textbooks from which practical information can be extracted was needed.

## **10. THE ROLE OF CIVIL SOCIETY ORGANIZATIONS**

Civil society organizations play a significant role in the effort to combat cancer. One essential element of treating cancer patients is that the patient – and society – needs to accept the fact that while cancer is a serious disease, it is not a death sentence. Changing public thinking in this regard is one of the hardest jobs there is. The opinions voiced and information provided by patients who have recovered are more valuable than professional arguments. These patients can offer the most credible information to society, to current patients, and to their families on how to fight the disease, on what problems they face during treatment, on how they recovered, and on how their lives have evolved as recovered cancer patients. If they invite people to screenings and encourage them to go, they are more credible. A number of patient advocacy organizations have recognized this and are acting on it. Their informative work and patient support are contributing to the success of the National Cancer Control Programme.

Civil society organizations such as the Hungarian Cancer Control League, the National Federation of Cancer Patients, and the Foundation Against Cancer, for People and for Tomorrow have significant opportunities to shape the health consciousness of the citizens. They work to evolve healthy lifestyles and to help citizens maintain their health. They offer health education and help to design ways of implementing health promotion theory in practice. Civil society organizations are successful in motivating people to respond to invitations to attend screenings. They contribute to the successful rehabilitation of cancer patients, and to their readjustment to society.

Various environmental organizations can undertake similarly significant roles in prevention by calling attention to the ways in which certain materials damage the environment and are health hazards that often cause cancer.

Several civil society and professional organizations are working in cooperation with one another to promote healthy nutrition and combat obesity, which also plays a significant role in cancer prevention. Their work is of key importance to school education, and in promoting the health of future generations.

It is important that information provided for patients – on examinations and treatment – be professional and easily understandable. A cancer patient must have appropriate information on his or her disease and on the actions being taken with and around him or her, as well as on the reasons why waiting is necessary or why deterioration in their condition may occur.

The civil society organizations and patient advocacy societies can help cancer patients to overcome emotional tension during the treatment and rehabilitation periods. They can boost their willingness to fight and improve their quality of life by increasing their ability to coexist with the disease.

# 11. QUALITY CONTROL IN IMPLEMENTING THE NATIONAL CANCER CONTROL PROGRAMME

Improving the level of cancer care and coordinating treatment on European level first requires the elimination of differences in care from one place to the next, for differences limit patient chances to access care of appropriate quality. The most important goals are to reduce cancer mortality, to improve quality of life for cancer patients, to boost the level of care, as well as to promote the adaptation of research achievements to practice.

Steps in the quality improvement programme



The quality control of the National Cancer Control Programme is to be implemented within the framework of Donabedian's triad of structure, process and outcome, in keeping with the steps outlined in the foregoing.

## Defining the quality levels of cancer care

When categorizing European oncology institutions by quality, European professionals base themselves on the "Comprehensive Cancer Centre" concept defined by the United States National Cancer Institute. It lists the following features as requirements for a comprehensive oncology centre:

- *a)* ability to maintain a global perspective and treatment options for cancer,
- b) presence of multidisciplinary diagnostic methods,
- *c)* equally able to handle prevention, patient care, patient follow up, and continuing care,
- *d)* translational research.

When defining the quality levels of cancer care, the Organization of European Cancer Institutes (OECI) set up five categories to determine comprehensiveness:

- 1. Cancer Registry,
- 2. Cancer Care Unit,
- 3. Cancer Care Department,
- 4. Cancer Care Centre,
- 5. Comprehensive Cancer Centre.

The first step in European coordination was to determine the type of institutes that OECI member institutions were classified in, and the manner in which they treated cancer patients. The database formed in this way was an essential first step. It was the basis on which OECI prepared a questionnaire to vet the oncology institutes and determine the quality category of the care they provided.

National Public Health and Medical Officers' Service monitors the existence of the personnel and equipment conditions for treating cancer patients in Hungary and it also issues the operation licence enabling them to conduct their activity.

The OECI quality control proposal for surveying the level of cancer care

Using the OECI questionnaire and manual, the various institutes can measure their own quality levels, which is a preparatory step towards attaining their own European cancer care accreditation. There are two major components of European accreditation, which correspond to the different levels of comprehensiveness:

- 1. The general regular quality control system or an advanced version of it,
- 2. The existence of satisfactory conditions for being listed in a quality category, as monitored and certified by oncology experts during an onsite visit.

The goal of a common accreditation of cancer centres in Europe is to assure that throughout Europe but particularly in the European Union, the content of cancer care is identical and does not fluctuate.

The condition for the European accreditation of the cancer care facilities is knowledge of up-to-date methods (evidence-based guidelines and protocols) and use of these methods in clinical practice. The first step is the elaboration of standards, options, and recommendations (SOR) for future practice, which provides an algorithm to assist patient care in various aspects of day-to-day therapy. The SOR project includes the priorities of primary procedures (diagnosis, definition of stage, prevention, first line of treatment, and patient monitoring), for both adult and paediatric cancer.

The audit exercises of the accreditation process have to extend to evaluating organization and administration, personnel and management, equipment and installations, professional policy and procedures, and the education and training of personnel and the outcomes. Once the standards exist, a series of comprehensive guidelines can be introduced to update the primary course of treatment for the most frequent and most important cancer encountered in Hungary.

# **FUTURE OF CANCER CARE**

The overall aim of the National Cancer Control Programme is to halt the growing trend of tumour mortality, the attainment of which requires action and progress in the following fields:

#### **OBJECTIVE 1: CONTROLLING THE OCCURRENCE OF FACTORS THAT PLAY MAJOR ROLES IN THE DEVELOPMENT OF MALIGNANT NEOPOLASMS BY RAISING THE EFFECTIVENESS OF PRIMARY PREVENTION AND THROUGH PROMOTING PUBLIC AWARENESS AND ACCEPTANCE**

Tasks:

- 1. To arrange for ongoing surveillance and monitoring of the population's health, and to see to it that the trends of harmful health determinants are analysed on an ongoing basis.
- 2. To organize comprehensive information and awareness raising programs that are tailored to the needs of target groups in order to provide health education, to make people adopt healthy lifestyles and to properly evolve healthy attitudes in life.
- 3. To achieve a gradual decrease in the proportion of environmentally harmful factors that play a role in tumour formation.
- 4. To enhance activities aimed at preventing people from taking up health damaging behaviours (e.g. alcohol abuse) and habits (excessive sunbathing) and at kicking these habits, furthermore activities aimed at evolving the need for good personal hygiene practices.
- 5. To undertake activities in order to control smoking, including measures to make legislation on the protection of non-smokers stricter and to put in place effective quit smoking programmes.
- 6. To promote the evolvement of healthy dietary habits and to facilitate the creation of the necessary conditions for active physical exercise on a daily basis and for physical education at school.
- 7. To mobilise NGOs and civil society in order for them to be actively involved in implementing the aforementioned actions.
- 8. To urge that health plans at the community level are formulated or reviewed in keeping with the aforementioned considerations and that health impact study findings are taken into full consideration in community decision-making.

Deadline: ongoing

## DIAGNOSING MALIGNANT NEOPLASMS AT THE EARLIEST POSSIBLE STAGE IN ORDER TO ENABLE EFFECTIVE TREATMENT, THROUGH INCREASING THE EFFICIENCY, PUBLIC AWARENESS AND ACCEPTANCE OF SECONDARY PREVENTION (SCREENING)

## Tasks:

- 1. To use all available means in order to increase attendance rates at organised population-based screening and to achieve that the highest possible proportion of agegroups that are most at risk shall, or could, attend screening.
- 2. To deploy mobile screening stations in a programmed manner, thereby increasing coverage by, and attendance at, screening programmes in areas most in need.
- 3. To further strengthen and promote the activities and involvement of NGOs, different initiatives by churches and the supporting role of the business sector.
- 4. To develop health conscious behaviours of individuals and to strengthen their skills of self-examination and early identification of signs that are suspicious for cancer.

Deadline: ongoing

## IMPROVING THE QUALITY OF CARE OF CANCER PATIENTS BY BRINGING CANCER CARE SERVICES IN LINE WITH THE EUROPEAN SYSTEM THROUGH EVOLVING A UNIFIED SYSTEM OF CANCER TREATMENT CENTRES

## Tasks:

After undertaking a review of the personnel and objective conditions at service providers who hold licences to carry out specific cancer care activities:

1. To define criteria for designating county-level and regional cancer care centres and to make providers' pre-qualification results public.

Deadline: 30 September 2006

2. To create a system of county-level and regional cancer care centres that ensures equity in access to care.

Deadline: 1 January 2007

3. To certify institutions and care settings that are involved in the provision of cancer treatment and care, taking into account European accreditation criteria.

## PREPARING PRIMARY HEALTH CARE TO ASSUME A ROLE IN CANCER CARE IN ORDER TO ENHANCE THE EFFICIENCY OF EARLY DETECTION OF CANCER

Tasks:

1. To organise thematic continuing education courses for primary health care personnel on the basic principles and practices of cancer screening, care, follow-up and continuous care, current and effective pain control methods, as well as on possibilities of medical device supply and modalities of rehabilitation.

Deadline: ongoing from 30 June 2006 onwards

2. To evolve conditions for regular contacts between family practitioners and cancer treatment centres, to ensure that such contacts are technically regulated and supervised.

Deadline: 30 June 2006

## DEVELOPING THE CONDITIONS FOR STATE-OF-THE-ART TUMOUR DIAGNOSIS IN ORDER TO IMPROVE THE EFFECTIVENESS OF MEDICAL TREATMENT

Tasks:

1. To ensure that imaging techniques are applied with appropriate quality and efficiency, by means of evolving adequate technical and financing rules and by checking compliance with such rules.

Deadline: 31 December 2006, subsequently ongoing

2. To accelerate the use of diagnostic molecular pathology.

Deadline: from 1 January 2007 ongoing

3. To accelerate the evolvement of the necessary conditions for telemedicine, and within it, of diagnostic telepathology, in order to increase the efficiency and improve the quality of diagnosis, by establishing digital microscopic reference portals using internet protocol.

Deadline: 31 December 2007, subsequently ongoing

4. To improve the operating conditions of radiation oncology diagnosis and to upgrade the equipment stock.

## IMPROVING THE QUALITY OF LIFE OF CANCER PATIENTS BY INTRODUCING STATE-OF-THE-ART TUMOUR SURGERY TECHNIQUES

Tasks:

1. To se to it that the conditions for performing surgery for remote metastases, conservation surgeries and reconstructive surgeries are available in all cancer care centres.

Deadline: 31 December 2012

2. To achieve that cancer surgery only may be performed on the basis of a decision made by a multidisciplinary cancer care team.

#### IMPROVING RADIATION THERAPY POSSIBILITIES AND UPGRADING RADIATION THERAPY EQUIPMENT STOCK IN ORDER TO INCREASE DISEASE FREE SURVIVAL, IMPROVE QUALITY OF LIFE AND DECREASE WAITING TIMES

#### Tasks:

1. To draw up a detailed national development plan for the radiation therapy machine stock in keeping with the joint criteria of the International Atomic Energy Agency (IAEA) and the European Society of Therapeutic Radiology (ESTRO), by an independent expert panel to be set up separately.

Deadline: 31 July 2006

- 2. To replace amortized (more than 10 year-old) linear accelerators.
- 3. To increase the number of supervolt therapy equipment, taking into account the size of population to be served and the number of available radiation therapy equipment.
- 4. To gradually replace cobalt beam therapy units older than 10 years by linear accelerators.
- 5. To establish a new state-of-the-art radiation therapy centre in the Central Trans-Danubia region.
- 6. To ensure the availability of current brachytherapy in all radiation therapy centres.
- 7. To gradually replace afterloading equipment that is older than 10 years.
- 8. To create the technical and financing conditions for permanent I-125 seed implantation.
- 9. To install CT simulators to complement existing simulators in radiation therapy centres with 3 or more high-energy radiation therapy equipment, or to replace amortised simulators older than 10 years by CT simulators.
- 10. To equip all newly installed linear accelerators with multi-leaf collimators and electronic portal imaging device (EPID) at the very time of their installation.
- 11. To gradually put in place the necessary conditions for intensity-modulated radiotherapy in radiotherapy centres.
- 12. To ensure the availability of appropriate health personnel as a precondition for any development.

## IMPROVING CONDITIONS OF DRUG AND BIOLOGICAL THERAPY IN ORDER TO ENHANCE TREATMENT OUTCOMES AND IMPROVE THE QUALITY OF LIFE OF CANCER PATIENTS

## Tasks:

1. To bring clinical cancer care beds in line with WHO standards and to increase hospital capacities required for the delivery of cancer treatment of appropriate quality.

Deadline: 31 December 2010

2. To achieve that patients with malignant neoplastic disease are provided chemotherapy in cancer care centres.

Deadline: 1 March 2006, subsequently ongoing

3. To provide incentives to the effect that conditions are created at cancer care wards that allow the delivery of treatment regimes.

Deadline: 1 January 2008

4. To gradually introduce state-of-the-art biological therapies that have been incorporated in clinical practice, including treatment modalities based on monoclonal antibodies, the use of growth factors and cytokines, immunisation against tumours, anti-angiogenesis therapy, gene therapy, tumour growth inhibition and immunomodulation techniques.

Deadline: 31 December 2007, subsequently ongoing

### INTEGRATING, FROM A PROFESSIONAL POINT OF VIEW, ONCOLOGICAL CONTINUING CARE FACILITIES WITH CANCER CARE CENTRES AT THE COUNTY LEVEL, IN ORDER TO ENSURE SEAMLESS CARE FOR CANCER PATIENTS AND TO ENHANCE THE EFFICIENCY OF PATIENT MANAGEMENT

## Tasks:

1. To undertake the revision of oncological continuing care facilities and to use the finding of the exercise to inform the formulation of detailed proposals concerning the updating of their operation.

Deadline: 31 December 2006

2. To make continuing care facilities ready and prepared for getting involved in comprehensive care activities as well as for engaging in efficient collaboration with cancer care centres and primary health care services.

## ENHANCING EQUAL OPPORTUNITIES FOR CANCER PATIENTS THROUGH DEVELOPING COUNTY-LEVEL AND REGIONAL CENTRES

Tasks:

1. To set up multidisciplinary cancer care teams and to insert their terms of reference into institutional operating rules.

Deadline: 30 June 2006

2. To review the referral scheme and responsibility to provide in-area care of countrylevel centres.

Deadline: 1 January 2007

3. To review the level of machine and equipment supply of county-level and regional centres and to assess their development needs.

Deadline: 30 June 2006

4. To achieve that the Central Trans-Danubia regional cancer care centre is up and running.

Deadline: 1 January 2007

FOR CREATING CONDITIONS **NECESSARY** THE **NATIONWIDE COORDINATION** CANCER CARE SERVICES, **INCLUDING** OF THE DEVELOPMENT OF INFORMATION TECHNOLOGY AND DATA PROVISION SYSTEMS RELATED TO CANCER CARE ACTIVITES AND TUMOUR INCIDENCE. IN ORDER TO DELIVER UNIVIED HIGH-STANDARD AND EFFECTIVE PATIENT CARE AND TO ENHANCE THE RELIABILITY OF **CANCEER MORBIDITY AND MORTALITY STATISTICS** 

Tasks:

1. To evaluate the operation of the National Cancer Registry and to make proposals for changes based on the findings of the evaluation.

Deadline: 31 December 2006

2. To review undergraduate and postgraduate training programs in the fields of cancer prevention and cancer treatment related knowledge, ant to formulate a proposal as to how such information and knowledge should be incorporated into different curricula.

Deadline: 1 June 2007

3. To evolve a system of continuing education of those involved in the care of cancer patients, to ensure that they have high-level current knowledge, by using state-of-the-art infocommunication technologies, too.

Deadline: 31 December 2007

4. To create, on the regional and national levels and by applying telemedicine, consultation possibilities, including familiarisation with novel forms of care and diagnostic procedures as well as the exchange of experience gained in the course of treating rare diseases.

Deadline: ongoing from 31 December 2007 onwards

5. To establish a joint consultation system for pathologists and cytopathologists.

Deadline: 31 December 2006

6. To create online connections in the system of the network of cancer patient care settings which may be used for the follow-up of patient pathways in all forms of care delivery, for transferring findings and test results to the attending physician without any time delay, and which at the same time meet the requirements of the health reporting system (including the Cancer Registry).

Deadline: 30 June 2008

7. To make sure that the system of 'DrInfo' has relevant information concerning the implementation of tasks spelled out under the objectives of the National Cancer control Programme.

Deadline: ongoing from 1 January 2007 onwards

## EVOLVING A COMPREHENSIVE REHABILITATION SCHEME FOR CANCER PATIENTS IN ORDER TO ENHANCE THEIR REINTEGRATION INTO SOCIETY AND THE FAMILY

Tasks:

1. To gradually evolve dedicated cancer rehabilitation inpatient and outpatient capacities through structural modifications.

Deadline: ongoing from 1 January 2007 onwards

2. To make sure that pain clinics are established and operated at each of the regional and county-level cancer care centres.

Deadline: ongoing from 1 January 2007 to 2009

3. To make sure that psychological counselling services are made available for patients and relatives at each of the cancer care centres.

Deadline: ongoing from 1 January 2007

# CREATING A COUNTRYWIDE HOSPICE NETWORK IN ORDER TO IMPROVE THE QUALITY OF LIFE OF CANCER PATIENTS

Tasks:

1. To establish, by the year 2010, at least one hospice by region, operating as part of the social insurance scheme.

Deadline: ongoing from 30 June 2006 to 2010

2. To achieve countrywide coverage of hospice care delivered within skilled nursing care services at home, in 3 stages (in counties, towns and their surroundings, in the whole country).

Deadline: 31 December 2007 (Stage one)

31 December 2008 (Stage two)

- 31 December 2011 (Stage three)
- 3. To provide for the professional representation and presence in education and training of hospice, and to integrate the relevant body of knowledge into education and continuing education.

## PROVIDING EDUCATION THAT CONFORMS TO EUROPEAN STANDARDS FOR HEALTH PROFESSIONALS (SPECIALIST EDOCTORS, NURSING AND ALLIED HEALTH PERSONNEL) WHO ARE INVOLVED IN CANCER TREATMENT ACTIVITIES IN ORDER TO ENHANCE COMPREHENSIVE CARE FOR CANCER PATIENTS

Tasks:

1. To launch specialisation training courses for nursing and allied health personnel working in the specialist discipline of cancer care.

Deadline: 1 September 2006

2. To launch continuing education for nursing and allied health personnel working in the fields of oncological diagnosis and hospice care.

Deadline: 1 September 2006

3. To update continuing education for specialist doctors working in cancer care and to implement regular reviews of both the teaching material and the applied methodology.

Deadline: 31 December 2006

4. To draw up a program in order to make sure that health manpower needs of cancer care services, that may be planned in advance, are met.

Deadline: 30 September 2006

5. To make efforts to achieve that specialist qualifications in medical oncology becomes a firs specialist qualification.

Deadline: 1 September 2007

## STRENGTHENING QUALITY CONTROL IN ORDER TO CREATE UNIFORM AND HIGHER QUALITY STANDARDS IN CANCER CARE SERVICES

Tasks:

1. To draw up annual national work programmes for the oncological professional supervisory system.

Deadline: annually from 31 March 2006

2. To regularly revise operating licences of cancer care settings, with special regard to compliance with procedures contained in clinical protocols.

Deadline: every other year from 1 September 2006 onward

3. To operate internal quality control and external quality management systems in keeping with provisions of legislation in force, in all healthcare facilities providing care for cancer patients.

Deadline: ongoing from 31 December 2006

4. To make preparations for the European Union accreditation of cancer care settings.

Deadline: ongoing from 1 January 2007

5. To develop structure-process-outcome indicators that would promote quality control in the framework of National Cancer Control Programme implementation.

Deadline: ongoing from 31 December 2006

## INVOLVING CANCER CARE PATIENTS AND THEIR RELATIVES AND ALL THOSE TAKING PART IN THE DELIVERY OF CANCER CARE

Tasks:

To set up a Programme Council with membership made up of representatives of stakeholder NGOs and professional organisations, relevant line ministries and national agencies, and tasked with the mandate of assisting and monitoring National Cancer Control Programme implementation, and elaborating proposals for amendments that might become necessary in the course of implementation.

Deadline: 1 March 2006

## ANNEXES





Source: NEJ 2004

## Figure 2: Age-specific morbidity, females, 2002.



Source: NEJ 2004



Figure 3: Standardised cancer mortality rate

Source: WHO 2004

Figure 4: Potential Years of Life Lost due to malignant neoplasms per 100,000 population



Source: OECD HEALTH DATA 2004.



Figure 5: Potential Years of Active Life Lost due to cancer mortality

Source: Central Statistical Office Demographic Yearbook, 2004





Source: Central Statistical Office, 2004



Figure 7: Cancer mortality per 100,000 population, females, Hungary

Figure 8: Male cancer morbidity in order of occurrence, 2000-2003, Hungarian National Cancer Registry (morbidity %)



Source: Hungarian National Cancer Registry, 2004

Source: Central Statistical Office, 2004

## Figure 9: Female cancer morbidity in order of occurrence, 2000-2003, Hungarian National Cancer Registry (morbidity %)



Source: Hungarian National Cancer Registry, 2004



Figure 10: Patients registered with continuous/follow-up care services

Source: National Statistical Data Collection Program, 2002



# Detection of new cases of malignant neoplasms, 2002

Figure 11:





Figure 12: Tobacco-related premature mortality in Hungary, 1978-2003

Source: WHO HFA Mortality Database, 2005

Prevention strategy									
Type of cancer	Avoid tobacco use	Increase physical activity	Control weight	Healthy diet	Limit alcohol consumption	Avoid excess sun exposure			
Breast		V		ъ	Ъ				
Colon				V	Z				
Lang	V			V					
Oral cavity	V			Ā	Ŋ				
Oesophagus			V	V	Z	V			
Uterus	V		$\checkmark$						
Prostate				A					
Pancreas				V					
Bladder									
Kidney	V		V						
Stomach									
Skin						N			

# Table 1. Modifiable risk factors for cancer prevention

Source: Stein et al.: Br. J. Cancer 2004, 90: 299-303

Туре	STANDARDISED MORTALITY RATES WORLDWIDE											
of cancer	1976-1977		1984-1986		1988-1991		1990-1993		1992-1995		1994-1997	
	Mortality	Rank order	Mortality	Rank order	Mortality	Rank order	Mortality	Rank order	Mortality	Rank order	Mortality	Rank order
Oral cavity	7.6	7	13.0	6	14.7	1	17.0	1	18.5	1	20.0	1
Stomach	47.4	4	34.9	7	24.0	8	23.4	11	22.1	14	18.8	18
Colon	28.5	11	35.0	4	29.0	2	30.8	2	32.0	2	34.3	2
Lang	65.6	11	87.6	6	76.4	1	81.6	1	84.1	1	85.6	1
Prostate	23.9	6	24.1	19	15.7	22	15.8	19	18.5	16	18.7	11
Leukaemia	7.6	13	9.3	3	7.2	1	7.2	3	7.2	2	7.4	1
All cancers	256.9	5	294.9	1	246.5	1	258.7	1	285.0	1	272.2	1

# Table 2. Cancer mortality rates, 1976-1997, males

*Source: GLOBOCAN 2000, Cancer Incidence, Mortality and Prevalence Worldwide, Version 1.0* Rank order: Position Hungary occupies in terms of malignant cancer mortality in group of 45-50 countries worldwide.

Type	STANDARDISED MORTALITY RATES WORLDWIDE											
of cancer	1976-1977		1984-1986		1988-1991		1990-1993		1992-1995		1994-1997	
	Mortality Rank order		Mortality	Rank order								
Oral cavity	1.4	20	1.9	10	1.7	5	2.2	2	2.4	1	2.4	1
Stomach	22.6	4	15.8	8	10.2	10	9.9	16	9.7	14	8.7	18
Colon	22.6	12	24.2	3	18.1	2	18.5	2	19.0	1	18.7	2
Lang	11.2	12	14.9	13	14.9	12	16.6	7	17.9	5	20.3	5
Breast	23.8	19	26.1	20	22.6	15	23.4	9	23.9	8	23.7	6
Cervix uteri			8.5	10	6.8	7	6.5	8	6.3	8	6.5	10
Uterus other parts	19.6	5	7.0	9	5.0	11	5.0	11	5.0	8	4.8	13
Leukaemia	5.1	10	5.5	4	4.6	2	4.5	3	4.1	1	4.4	4
All cancers	163.6	4	164.4	3	131.5	3	135.2	2	138.0	2	138.4	2

# Table 3. Cancer mortality rates, 1976-1997, females

**Source:** GLOBOCAN 2000, Cancer Incidence, Mortality and Prevalence Worldwide, Version 1.0 Rank order: Position Hungary occupies in terms of malignant cancer mortality in group of 45-50 countries worldwide.

Table	4.
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Speciality	Nu							
	2000	2002	2003	2004	2005	Doctors obtaining specialist qualification, in 2000-2005, total	Doctors studying for specialist qualification	Doctors with specialist qualification, 2004
Cytopathology	0	63	28	2	0	93	3	93
Haematology	19	10	6	4	2	41	16	83
Clinical oncology	36	21	36	84	17	194	87	365
Pathology	15	11	8	8	5	47	48	105
Radiation therapy	4	2	1	6	6	19	18	54

Source: Ministry of Health, 2005.



