Executive summary

Health Council of the Netherlands. Familial hypercholesterolaemia and the Medical Examinations Act. The Hague: Health Council of the Netherlands, 2001; publication no. 2001/26

Familial hypercholesterolaemia (FH) is a hereditary disorder of the fat metabolism which predisposes to premature atherosclerosis, due to an increase in cholesterol levels. FH presents itself in a homozygous or a heterozygous variant. The homozygous variant is a vary serious disease, that occurs in the Netherlands to approximately one in a million individuals. It is estimated that some 40,000 people in the Netherlands have the heterozygous variant of FH. The risk of premature death due to cardiovascular disease among carriers of a gene mutation for FH is four times higher than among the population at large. Life expectancy is shortened by about ten years if FH goes untreated. Most of FH carriers are not aware of their disorder. Because nowadays effective treatment is available, pleas for early screening are being made (GR90, GR00).

In recent years there has been growing concern in society about access to important insurance policies for FH carriers. Many of the FH carriers who took part in the FH screening programme have apparently had their premiums raised or been refused cover when trying to take out insurance. Problems of this kind are seen as a major obstacle to the successful stepping-up of the screening programme which the Minister of Health, Welfare and Sports decided upon in 2001. In particular, there is some doubt as to whether the Medical Examinations Act provides sufficient protection for FH carriers when taking out insurance for a pension, life insurance or disability insurance.

The protection the Act provides depends partly on whether FH is an ‘untreatable’ and ‘serious’ disease in the meaning of Section 3. The Minister put this question to the

Health Council, along with that of the life expectancy of people with FH who are receiving treatment for it.

The Medical Examinations Act does not as such define the terms ‘treatable’ or ‘serious’. But it can be deduced from the wording of Section 3(2)a that a disease is deemed treatable for the purposes of the Act if

a the disease can be cured, or
b the development of the disease can be prevented by medical intervention, or
c the development of the disease can be stabilized by medical intervention.

Any judgement on whether one of these criteria obtains must be based on current medical knowledge, taking into account the aim and purport of the Act.

The committee considers carriership of FH as a latent disease in the context of the Act. Without gene mutation one can not get FH, but carriership of FH need not necessarily result in an increase in cholesterol levels and clinical manifestations of disease. FH is a manifest disease if the carrier develops coronary heart disease (CHD).

The committee considers that FH is a treatable disease in the meaning of Section 3. It is true that FH is not treatable at the level of the gene defect – the defect underlying FH cannot at present be cured or prevented. But an increase in cholesterol levels can – by means of cholesterol-reducing therapy combined with a healthy lifestyle – be treated effectively. As a result of that the progression of atherosclerosis can be reduced, or even cause regression of the vascular condition, and in a large number of cases the occurrence of a CHD can be prevented or, if that is not the case, a second CHD can be prevented or postponed. This means that medical intervention can produce a substantial increase in life expectency. It is above all the (primary) preventive effect on CHD that leads the committee to regard FH as a treatable disease in the meaning of Section 3 of the Act.

The committee also considers that FH must be deemed a serious disease in the meaning of the Act. The principal manifestation of FH – a CHD – is a serious condition, and the risk of this, without treatment, is substantial. The fact that CHD can often be prevented does not make the disease any less serious.

Does treatability also mean that life expectancy can be normalized? The committee found indications – though not proof – that therapy can virtually normalize life expectancy of people with FH, provided it is started in time (by which the committee in principle means adolescence). The committee does expect, however, that intensive therapy could substantially increase life expectancy even if started at a later age. It founds this expectiation on regression experiments in populations of middle aged

people with FH. A healthy lifestyle (no smoking, physical activity, diet) enhances the benefits of cholesterol-lowering therapy.

Having answered the questions put by the Minister, the committee briefly considers what these answers mean to FH carriers. As FH is treatable, the Act does not in principle limit the right of insurers to ask questions and carry out investigations in respect of FH. It follows from Sections 3 and 5 that investigating and asking questions about the risk of – latent or manifest – FH as part of a medical examination is legitimate. Only asking questions about (the results of) genetic investigations into FH is not permitted below the 'question limit' (as of 1 January 2001 in the case of life insurance, NLG 321,300 and in the case of disability insurance, NLG 64,260 for the first year and NLG 42,840 for following years).

In practice insurers can circumvent this latter prohibition by asking questions about cholesterol levels, whether the applicant is being treated by a specialist and, in the family history, causes of death and ages at death of relatives. In the case of FH carriers the answers to these questions, taken in conjunction, at least give an indication that their raised cholesterol levels are due to hereditary factors. Also, FH carriers often tell the insurer the results of genetic investigations without being asked, because they are not aware of what genetic information the Act requires them to give an insurer. The committee would therefore advise the Minister to see to it that more detailed rules are laid down on the permissibility of questions whose answers provide information on the applicant's hereditary characteristics. Apart from that it recommends that insurers oblige themselves to make clear to applicants what information he or she is required to give. Also improvements should be made in the public publicity on this matter.

Lastly, the committee concludes that, as the Act does not interfere with the freedom of insurers to set their own policies on premiums and acceptance, its answers to the questions put by the Minister only partly allay the concern felt in society about the position of FH carriers when taking out insurance. To allay this concern it needs to be evident that insurers base their premium and acceptance policies on accepted medical understanding, in particular as regards the treatability of diseases. Only if insurers base their assessment of risk on accepted medical understanding will the assumption upon which the Act is founded, that treatable diseases are in principle insurable, be justified. The committee therefore recommends that insurers make it clear how they gauge risk in the case of insurance for FH carriers.