

Charter for European Cardiovascular Disease Patients

Preamble

Cardiovascular disease (CVD) (the main forms of which are coronary heart disease and stroke) is the main cause of death in the EU, accounting for over 2 million deaths each year. Coronary heart disease itself is the single most common cause of death in the EU, leading to 741,000 deaths per year. Stroke is the second single most common cause of death in the EU, accounting for just over 508,000 deaths in the EU each year.

It is estimated that more than 10 million people live with CVD, making it one of the largest community of patients in Europe.

The aim of the Charter for cardiovascular patients is to ensure a high quality of life, free of avoidable disabilities, and also allow patients to continue their professional lives where appropriate. It sets out prerequisites to achieve the aim, comprising provisions for cardiovascular patients from early assistance in acute cases to treatment, rehabilitation and secondary prevention. It may be seen as aspirational, but what it does, in essence, is emphasise the need to ensure that good practice is in place and in accordance with widely-acknowledged professional guidelines.

The Charter recalls the need for a centralised, comprehensive European cardiovascular diseases registry. A central registry with comparable data would provide an effective tool for assessing quality of care and patient outcomes.

Article 1

Emergency Skills and Procedures

To minimise medical consequences for people who suffer acute events

- 1.1 School curricula should contain skills-training lessons for young people teaching them the essential actions needed to maintain life in case of emergency. All workplaces and public areas should have at least one person who is trained in First Aid to include basic life support skills.
- 1.2 Public places (schools, shopping centres, theatres, busy streets, bus/railway stations, airports, stadia, etc.) should provide access to automated external defibrillators and should have designated personnel who can use this equipment. Defibrillators should also be accessible in isolated areas, where it may take longer for an ambulance to arrive. The placement of defibrillators should be clearly indicated by signposting that is instantly recognisable.

- 1.3 Emergency ambulance service should be swift. Depending on the infrastructure, mean time between call and ambulance arrival at the place from where call is made should be between 8 and 15 minutes. These ambulances should be equipped with at least a defibrillator. Where national ambulance guidelines exist, ambulance equipment must be in accordance with them.
- 1.4 "Door to needle" e.g. time from hospital door to intervention, should be less than 60 minutes.
- 1.5 "Door to balloon" time, e.g. time from hospital door to intervention, should be less than 90 minutes.
- 1.6 Properly staffed and fully resourced stroke units, 24/7 thrombolysis and rapid-access TIA services must be established in a sufficient number of clinics and hospitals to cover the need of the country's stroke patients.

Article 2

Diagnosis

To optimise treatment and establish a partnership between health professionals and patients

- 2.1 To ensure optimal diagnosis, hospitals and medical centres should possess the necessary equipment and specially trained staff in sufficient quantities to cover the need of the population living in the surrounding area of the hospital/medical centre.
- 2.2 Healthcare professionals must ensure that patients fully understand the nature of their diagnosis and its medical consequences. They must carefully explain the various treatment options, their benefits and risks. Everything should be put in place to ensure patients can make an informed decision. Patients should expect to be kept informed about all developments regarding their conditions, including the important benefits of rehabilitation.
- 2.3 When patients are diagnosed with a cardiovascular disease, the healthcare professional should seek to involve patients' relatives as they will automatically become the first day-to-day caregiver. Patients suffering from inherited cardiac conditions (including familial hyperlipidaemia, cardiomyopathy and sudden arrhythmic death syndrome) should benefit from specific information sessions with their relatives at specialist centres with appropriately trained staff.

Article 3

Treatment standards

To ensure the best outcomes

- 3.1 When treatment is needed, the waiting time should never jeopardise the life or health status of a patient.
- 3.2 Patients have the right to a quality of care which is characterised by high technical standards as set out in professional guidelines.
- 3.3 Patients should have wide access to healthcare professionals for any question they may have, e.g. on risks inherent to the treatment.

- 3.4 When an invasive procedure is proposed, patients should expect their healthcare professionals to provide them with accurate information on the procedure, including access to rehabilitation.
- 3.5 Patients should expect to receive clear and understandable guidance on medication and its use and potential side effects from their healthcare professionals.
- 3.6 Mechanisms should be put in place to ensure the treatment is effectively implemented.

Article 4

Rehabilitation and Secondary Prevention

To sustain healthy lifestyles and avoid relapse

- 4.1 All eligible cardiovascular patients should benefit from a rehabilitation programme, including secondary prevention guidance. Referral to rehabilitation should be automatic. Patients' relatives should be encouraged to support patients during these programmes. Patients should receive the range of rehabilitation services they require for as long as they require them.
- 4.2 As every patient is different, the guidance and advice must be personalised and follow-up must be ensured.
- 4.3 After completion of a rehabilitation programme, patients should have access to continued support and counselling in healthy lifestyle.
- 4.4 Patients should benefit from help to return to live in their own home rather than being placed in a nursing home if they so wish.

Article 5

Partnership and Responsibility

To strengthen co-operation between patients and healthcare professionals and enhance social acceptance of patients and their needs

- 5.1 In the spirit of good relationship with the healthcare professional, patients do not only have rights; they also have responsibilities: to provide, to the best of their knowledge, information about their medical condition and history; to comply with the treatment and medication commonly decided with the healthcare professional; to report promptly to the medical or nursing staff any unexpected problems or changes in their medical condition.
- 5.2 To cope with their responsibilities, patients may benefit from assistance from patients groups. It is recommended that patients are informed, at discharge from hospital, about such groups. In several countries, heart foundations and cardiovascular patients' association offer assistance and peergroup support.
- 5.3 Beyond the partnership between patients and healthcare professionals, a wider societal responsibility exists. It is necessary to enhance social acceptability of cardiovascular patients need for cardiac rehabilitation and continued care and support. Patients should benefit from help to return to work.

5.4 Clear and unbiased information are the basis of disease self-management. This information should be provided by independent governmental bodies or independent non-governmental organisations, such as heart foundations or cardiac societies. It is recommended that patients follow self-help programmes that can facilitate medical management, improve social life and strengthen links between the patients.