Are you being heard?

Anyone living in the United Kingdom has a basic right to health and medical services from the National Health Services of England, Scotland, Wales and Northern Ireland. Many of the general principles, rights and expectations that HEART UK has incorporated into this charter may already be found in the NHS regions’ constitutions and guidelines (which are not legally binding). There is a need, however, for specific guidance for patients with lipid- and cholesterol-related health issues. The following points are designed to help patients and those treating them using existing methods. It is designed to encourage patients to take a more active role in understanding and managing their condition.

1 Diagnosis 1: Your GP should offer you a cholesterol test as part of the NHS Health Check when you reach 40. You may be tested before or after this age. For most people a healthy total cholesterol level is below 5mmol/L (for more information, visit heartuk.org.uk). If anyone in your family has had a heart attack or stroke or died before the age of 60 due to heart disease or stroke, or if there’s a family history of high cholesterol, you should have this test earlier.

2 Diagnosis 2: If you have raised cholesterol which is not controlled by diet and lifestyle changes, you may have inherited high cholesterol placing you at increased risk of cardiovascular diseases (heart attacks, strokes and angina). If your tests indicate a very high level of “bad” cholesterol, LDL, (low density lipoprotein) you may have familial hypercholesterolaemia (FH) or another inherited cholesterol condition. Cholesterol-lowering treatment may then be recommended even if you have no other cardiovascular disease risk factors.

3 Diagnosis 3: If there is a family history of early heart attacks or stroke or if you are diagnosed with FH, close family members (brothers, sisters and children) should have their cholesterol tested (also known as cascade testing) without waiting until they are 40 and ideally before the age of 10, as treatment is often recommended before the age of 18.

4 Tests: You should have the results of any test explained by your GP/hospital specialist/HCP (health care professional). Adults with raised cholesterol should be tested at intervals once treatment has been started.

5 Lifestyle: You should keep active and keep your weight down to a healthy level. You should eat a varied heart-healthy diet with cholesterol-lowering food. Avoid smoking and excessive alcohol. You should be given advice and support to follow a healthy lifestyle or access to a diettian.

6 Health assessment: You should have your blood pressure, weight, waist measurement, cardiovascular risk, thyroid, kidney and liver function and diabetes risk assessed as part of your health check or by your GP if you’re over the age of 40 and have never had a health check. Unless you have FH, cardiovascular disease, Type 1 diabetes or chronic kidney disease (CKD) your cardiovascular risk will be calculated with a computerised tool known as QRISK2. This risk assessment will guide your GP/HCP as to whether you should be offered treatment to lower your cholesterol.

7 Treatment 1: If your cholesterol remains high despite diet and lifestyle changes and/or your cardiovascular risk has been assessed as needing treatment (a risk of 10% or more of a heart attack or stroke in the next 10 years) you may be offered cholesterol-lowering drugs which will usually be a statin. If you have high blood pressure (hypertension), you may be prescribed medication for this. If you are diagnosed with FH, you may be referred to a hospital or clinic for confirmation of FH and for genetic testing if needed.

8 Treatment 2: You should take your medication as prescribed and promptly report any side-effects to your GP/ HCP for further advice. If you are following the diet and lifestyle advice you have been given and taking your medication regularly and your cholesterol levels are not responding, you may be referred to a specialised clinic.

9 Self-care and your responsibilities: You should help HCPs, and your family and loved ones, to deal with your condition. That often means substantial lifestyle changes, see point 5. Help your doctor and the NHS to help you through self-motivation, respect for the NHS and with family support. For example, keep appointments or take medication as prescribed. Health care should be seen as a partnership between you and the people treating you. You can refer to the HEART UK helpline for advice and help (see details below). You may be able to contact a HEART UK ambassador for additional support.

10 Information: You should be able to see and ask questions about your medical records, both those held by your GP and those at a hospital where you are treated for raised cholesterol. There may be a cost involved for a copy. You should ask to see any correspondence between your HCPs and your hospital/clinic regarding your condition.

For further advice: www.heartuk.org.uk/cholesterol-helpline or ring 0345 450 5988
(NB: A separate Notes and Appendix section providing background information about the NHS Constitution and patients’ rights is available on request)