Chapter 8 of the Coronary Heart Disease National Service Framework (‘Chapter 8’): Arrhythmias and Sudden Cardiac Death – A progress report

Chapter 8, which sets out markers of good practice and quality requirements for the NHS for the development of arrhythmia and related services, was launched in 2005. Much has happened over the last four years, but there is still an enormous amount to do.

The Department of Health and NHS Improvement, which supports the 28 cardiac networks across England, have been focusing on some specific projects at a national level and this is a brief report of that work.

**Sudden Cardiac Death and Inherited Cardiac Conditions**

This is a very complex clinical area, but a hugely important one. Inheritable heart conditions that show no symptoms can strike suddenly and cause a sudden cardiac death. Most sudden deaths of young people occur as a result of one of these conditions, and one of the main ‘triggers’ is thought to be sustained exercise. These considerations exacerbate the devastating effects that sudden cardiac deaths have – striking fit, young people and not allowing family and friends to say goodbye.

There have, in the past, been calls for screening either the whole population or perceived ‘at-risk’ groups, such as young athletes. Unfortunately, because of the number and complexity of the conditions in question, there are currently no tests that can determine accurately enough whether someone is at high risk, and then predict whether the condition will ever affect them. This makes things tricky, because if a young athletic person is told that they may be at risk, they will face the dilemma of whether or not to give up a sporting profession or start a family in the future.

Insurance premiums can also be adversely affected if someone has to declare that they may have a familial heart condition. Alternatively, tests may not pick up the presence of a condition and a sudden death may result anyway. All of this has led to the National Screening Committee (NSC) to conclude that a screening programme would not be effective at this time. The NSC, with the health departments of all the UK countries, are keeping an eye on research taking place in this area and will consider what future research might lead to an effective test for these conditions.

Chapter 8 states that where a sudden cardiac death has occurred, the NHS should do all it can to assess the risks to other family members and treat them according to that risk. The pathway is complex, involving coroners and pathologists at the start of the process to clinical geneticists and other specialist health service staff. Some key developments have taken place to ensure that those at risk are detected and referred to a high-quality specialist service. We have concentrated our efforts in three areas:

**Coroners and Pathology Services**

When a sudden death occurs, it is important to determine as quickly as possible whether that death was as a result of an inherited heart disease, and...
whether other family members might be at risk. This obviously depends on the knowledge and expertise coroners and coroners’ officers have, but also the availability of expert pathology help and advice for them. Although there is still much to do in terms of educating coroners and their officers, many of them are now picking up cases of this kind. A network of cardiac pathologists has also been established so that coroners around the UK have access to specialist cardiac pathology expertise when needed. A database was recently established for the cardiac pathology community and, in time, this should give us a lot of information on incidence, but also where good links are developing with coroners.

**Specialist Inherited Cardiac Conditions Services**

At the other end of the patient pathway are the specialist assessment services to which family members thought to be at risk are referred. There are about 20 centres in the UK providing this highly specialised service. We have to ensure that these services offer the highest quality assessment, treatment and care to those that are referred. A couple of years ago, the Department of Health in collaboration with others, issued a service ‘blueprint’ of what we expect these services to include. But this was really only the start of the process. We will be working with a number of local and national organisations over the next couple of years to draw up more accurate service and quality standards, audit how well the centres providing this service meet those standards and then consider designation of centres for the provision of these services. We will be working with specialist commissioning colleagues to ensure that only services fit for purpose provide assessment services in this highly complex clinical area.

Many people have been involved in the development of inherited cardiac conditions services over the last few years and together they are ensuring that those at risk are getting the support and care they need.

**Atrial Fibrillation**

The recent establishment of the Atrial Fibrillation Association (AFA) was both inspired and timely, and all those involved should be congratulated.

Atrial Fibrillation (AF) affects over 1% of the whole population; 4% of the over-65 population. The overall incidence of stroke is about 5% per year in people with the condition. This is a serious condition with serious consequences if not detected and treated properly. The work of AFA and other organisations is crucial in raising awareness of AF and working with other stakeholders to improve prevention and treatment.
At a national level, NHS Improvement has been conducting a major piece of work with clinicians, academics, patient organisations and others to understand how AF services are provided now and how they ought to be provided in the future. A consensus meeting was held at the end of 2008 and the results of the discussions at that meeting will soon be communicated. The Department of Health has also conducted a full cost-benefit analysis of providing AF services and this will form part of the communication.

But one of the key changes we have been progressing is how we improve primary care services to not only pick up those with AF but also prescribe medication to manage the condition and reduce the risk of stroke. It is thought that only around half of those with AF who should be prescribed anticoagulants to prevent stroke are receiving them. We have been looking at how we might change the AF inclusions in the GP contract and are making some headway with this.

**Heart Rhythm Management Devices**

Pacemakers, implantable defibrillators (ICDs) and new, more sophisticated heart rhythm devices are helping restore the quality of life of patients with arrhythmias. But traditionally, this country has had some of the lowest implantation rates in Europe and the rest of the world. In addition to this, implant rates vary across the country.

A taskforce was set up a couple of years ago with the aim of raising the rate of implants to a level that compares with the Western European average by 2016. Several pieces of work have been initiated to support this aim.

For a number of years now, the Department of Health (with Medtronic at the start of the process) has been funding the Network Devices Survey Group, to collect and disseminate information on implant rates to all cardiac networks, showing the network rates and those of constituent PCTs. Provision of this information alone is already having a positive effect on implant rates. We are now looking at how better use can be made of this information.

But what we must do in the future is discover why rates in this country remain low. Dr Janet McComb and her colleagues in Newcastle have been doing some work to understand practices in this area better. We will build on this work in the future to see where the barriers to provision are and then see how we can support the commissioning process to ensure that everyone who needs one of these important devices gets one.

**The Future?**

So what will we be focusing on in the future? Although there is still a lot of unfinished business in terms of sudden cardiac death and arrhythmia services, we can no longer consider these services in isolation. There is crossover and commonality with other heart diseases and treatments like heart failure and cardiac rehabilitation - two areas the service needs to focus more on in the future. But heart disease generally must be recognised as just one of several vascular conditions that need to be prevented. Heart disease, stroke, diabetes, kidney disease and other related conditions have now been brought together at a national level as a vascular disease programme. The future emphasis will clearly be on prevention as the underlying causes of all these diseases carry similarities. A programme of vascular checks for all people between the ages of 40 and 74 is being established as we speak.

But this also gives us the opportunity to look at how we improve services for those with chronic and long-term disease to the standards that those with acute illness are now experiencing. It will also allow us to focus more on inequalities and ensuring that everyone gets the same quality of service.

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