MANAGING CARDIAC RHYTHM DISORDERS IN THE UK: THE NEED FOR CHANGE

EXECUTIVE SUMMARY

UNDERSTANDING SYMPTOMS OF ARRHYTHMIAS

(see chapter 5)

Symptoms represent the way in which patients and families with heart rhythm disorders may tell their medical story.

These symptoms are:

1. Palpitation.
2. Blackout/T-LOC/falls/collapse.
3. Cardiac arrest/Sudden cardiac death, and
4. Other cardiac symptoms.

All of these symptoms may occur in patients with abnormally slow heart rhythms, (bradyarrhythmias), or abnormally fast rhythms, (tachyarrhythmias), or irregular heart rhythms. These symptoms, and any associated abnormalities, are often intermittent. Therefore, at the time a patient is seen, the rhythm may be normal, and an arrhythmia may not be considered as the cause of the symptoms. This results in repeated symptoms.

1. Palpitation (see chapter 6)

"Awareness of abnormal heart beat".

By palpitations patients usually mean one or more of the following detected as an abnormality of their pulse or a sensation in their chest:

- A very transient awareness of a disturbance heart rhythm.
- An enhanced perception of a normal heart rate and rhythm.
- A sustained (i.e. more than a second or two) rapid regular heart rhythm.
- A sustained rapid irregular heart rhythm.

These may occur alone or in conjunction with other cardiac symptoms. eg chest pain, breathlessness, or blackout (transient loss of consciousness - T-LOC).

It is important to realise that arrhythmia patients may have ***only*** an electrical heart fault. The rest of the heart's function may be completely normal. Even so a small proportion of these patients may have a high-risk of sudden cardiac death.

Arrhythmia symptoms may ***also*** occur in patients whose hearts are structurally diseased, e.g. by a heart attack which damages the heart muscle, heart valve malfunction, heart muscle weakness, overgrown heart muscle or heart abnormalities from birth, (congenital heart disease). Such patients are often at increased risk of sudden cardiac death due to a life-threatening arrhythmia. This risk needs assessment and control.

2. Blackouts/T-LOC (see chapter 10)

"Transient loss of consciousness with spontaneous recovery."

It is widely assumed that most blackout/T-LOC is due to a neurological cause, but this is not correct, the majority of blackouts are probably the result of reflex syncope (transient loss of consciousness). The cause of blackout/T-LOC is often not epilepsy even when associated with abnormal movements, and/or loss of bladder and bowel control, which commonly occur in cardiac or reflex syncope. A mistaken diagnosis of epilepsy may be given to patients with blackout/T-LOC, which results in the wrong treatment, which is then unsuccessful. Blackout/T-LOC may be caused by life-threatening arrhythmias, which may need urgent and effective treatment.

Epilepsy has an incidence of about 0.7-1.0% in the general population. It is estimated that between 20 and 30% of "epilepsy" patients are misdiagnosed. Therefore there may be more than 100,000 patients with the wrong diagnosis in the UK alone. The Government estimates that the misdiagnosis of epilepsy may cost the NHS at least £180m per annum.

Blackout/T-LOC may cause "falls", especially in elderly patients:

- Elderly patients who fall may have had blackout/T-LOC, but cannot remember the blackout, (retrograde amnesia).
- They simply believe they have had a fall.
- A causative arrhythmia may therefore go untreated, leading to serious consequences, e.g. head injuries, fractures and prolonged hospitals admissions.
- Falls costs the NHS more than £1bn per annum. Many recurrent falls may be preventable if an underlying arrhythmia was properly detected and treated.

Blackouts/T-LOC may occur in children. They are commonly misdiagnosed as epilepsy or behavioural abnormalities. However:

- Blackouts in children must prompt a search for evidence of a life-threatening arrhythmia, e.g. the long QT syndrome.
- Blackouts in children may be terrifying for patients and parents. If the diagnosis is in any doubt they need specialist care from a cardiac electrophysiologist if an arrhythmia diagnosis is suspected.

3. Cardiac Arrest/Sudden Cardiac Death (see chapter 21)

"Unexpected death - instantaneous, within an hour of symptoms, or unwitnessed – due to an arrhythmia."

Many patients who die of sudden cardiac death (SCD) have no warning symptoms. Many other patients have had previous heart attack(s), or have commonly complained of other cardiac symptoms. Between 75,000 and 100,000 patients suffer a sudden cardiac arrest in the UK each year and many of these deaths are premature and tragic. Over 400 children and young adults suffer sudden unexplained death each year; sudden death in young people occurs approximately 15 times more frequently when there is a (probably wrong) diagnosis of epilepsy.

The challenges are:

- To identify patients who are at increased risk of sudden cardiac death.
- To rescue more patients who suffer sudden cardiac death.

- To prevent these patients who have been rescued previously having a further sudden cardiac death and not being resuscitated, which would then be fatal.

SCD usually occurs in the presence of old or new damage to the heart, usually due to a heart attack (myocardial infarction). An important minority of patients, who are at risk of death due to inborn electrical abnormalities, do not have acquired heart damage. These abnormalities may often be predicted from their family history. Unfortunately too many of these patients die in the prime of life, when they are making important social and economic contributions and would continue to do so if their death were prevented.

4. Other Cardiac Symptoms

The symptoms of cardiac arrhythmia may not be typical and therefore may be misinterpreted. This leads to delays both in diagnosis and in the appropriate treatment being administered.

Patients with rhythm disturbances may also complain of:

- Breathlessness.
- Fatigue.
- Chest pain.
- Inability to exercise.

Some patients may not have many symptoms; some may have none, even when a significant arrhythmia is present. In these cases the arrhythmia may be found during a routine examination. However, once discovered, even an asymptomatic arrhythmia needs thorough evaluation, because some are associated with an increased risk of stroke or heart failure even though the patient is unaware of the rhythm disturbance.

TYPES OF ABNORMAL HEART RHYTHMS

(see chapter 4)

There are two main types of cardiac arrhythmia:

- Bradyarrhythmias (slow heart rhythms below 60 beats/min).
- Tachyarrhythmias (fast heart rhythms above 100 beats/min).

Bradyarrhythmias (see chapter 10)

The heart may beat slowly because the normal pacemaker of the heart (sinus node) fails due to disease (sick sinus syndrome) or to intense vagal nerve stimulation (for example, carotid sinus syndrome or reflex syncope). High grade block in the conduction system may also result in marked slowing of the heart. Very slow heart rates or long pauses of the heart lead to symptoms of dizziness or loss of consciousness, (blackout/T-LOC). If the heart stops for a very prolonged period (asystole) sudden cardiac death may occur.

Tachyarrhythmias (see chapter 14,16,18)

All parts of the heart muscle may beat spontaneously. Diseased heart tissue may beat more rapidly than the normal pacemaker of the heart. This condition, which is known as a tachyarrhythmia (generally more than 100 beats per minute), is described in terms of its site of origin, for example atrial, junctional or ventricular.

The most important and common sustained tachyarrhythmias are:

- Atrial fibrillation AF (and atrial flutter - AFL).
- Junctional tachycardia.
- AV nodal re-entrant tachycardia – AVNRT.
- AV re-entrant tachycardia – AVRT.
- Ventricular tachycardia – VT.
- Ventricular fibrillation – VF.

All tachyarrhythmias may cause palpitations but VT is often associated with loss of consciousness whilst VF very quickly leads to sudden cardiac death.

In addition, isolated extra beats (ectopic beats) may arise from all parts of the heart muscle. Although often causing palpitation, they are rarely serious in the absence of structural heart disease.

INVESTIGATION OF PATIENTS WITH SYMPTOMS OF ABNORMAL HEART RHYTHMS

(see chapter 5 & 27)

The principles of investigation of all patients with cardiac rhythm disturbances are set out below:

- Careful clinical history from the patient and other witnesses.
- Physical examination to define any structural heart disease.
- Appropriate blood tests, e.g. blood count, thyroid function.
- 12-lead ECG *
- An ECG recorded during an attack, (unless diagnosis already made).

Recording an ECG during an attack may require:

- 24hr ambulatory ECG monitoring.
- In-hospital ECG monitoring.
- Patient-activated ECG event monitoring and loop-recorders.
- Implantable ECG monitors – the ILR.

It may be necessary to **provoke** an attack or abnormality in order to record an ECG during symptoms using:

- Formal exercise testing.
- Tilt-table testing.
- Vagus nerve stimulation techniques.
- Intra-cardiac electrophysiological study (EPS).
- Drug-provocation.

If there is a suggestion of structural heart disease, further investigations, such as echocardiography, cardiac catheterisation, cardiac magnetic resonance (CMR), computed tomography and/or nuclear imaging, are needed to characterise the type and extent of disease.

If an inherited type of arrhythmia is suspected in a family, genetic testing is appropriate, and is becoming increasingly useful. Any patient who has a suspected cardiac arrhythmia should have a 12-lead ECG recorded and an appropriate report provided. An ECG reported as normal by a computerised ECG reading system is generally, but not always, acceptable. However an abnormal report requires further analysis by a qualified practitioner. High-risk patients should be admitted urgently and investigated without delay.

SCREENING FOR RISK OF ARRHYTHMIAS

(see chapter 24)

Some patients with heart diseases may be at risk of a serious cardiac arrhythmia, and need to be identified, assessed and treated. Screening is designed to achieve this

Two groups need to be screened, even when they have no symptoms:

a) Patients at potential risk of a serious arrhythmia from known structural heart disease, such as:

- Previous myocardial infarction.
- Dilated cardiomyopathy.
- Hypertrophic cardiomyopathy and other inherited cardiomyopathies.
- Congenital heart disease.

b) Relatives of patients with sudden death or genetic arrhythmia diagnoses, such as:

- Hypertrophic cardiomyopathy and other inherited cardiomyopathies.
- Long QT syndrome.
- Arrhythmogenic right ventricular dysplasia.
- Brugada syndrome.
- Other rare conditions.

There are several important high risk groups which should be specifically mentioned:

a) Patients with poor left ventricular function > 4 weeks after myocardial infarction.

Most sudden cardiac deaths occur in patients with acute or chronic (previous, healed) myocardial infarction and often there is no warning of the impending arrhythmia. However, these deaths can be prevented by undertaking risk stratification using the published evidence for decision-making. There is robust evidence that patients with poor left ventricular function (LVEF <30%) live longer after prophylactic ICD implantation.

b) Patients with inherited causes of sudden cardiac death.

Family members of patients with premature sudden death require specialist attention and detailed evaluation to assess their risk. Screening attempts to identify the presence of disease and to assess the risk of associated life-threatening cardiac arrhythmia. The exact screening process differs depending on the disease state which is being investigated and on individual family circumstances. Screening must be carefully undertaken in order not to alarm parents and children and must be designed not to identify risk unnecessarily (a false positive result) whilst retaining the ability to identify as many as possible of those who are at risk (high sensitivity). This is a difficult and expensive process. Resource-implications are considerable.

THE TREATMENT OF ARRHYTHMIAS

(see chapter 11,12 & 21)

Modern treatments for cardiac arrhythmias are highly effective & cost-effective. They compare very favourably with other heart treatments, such as bypass surgery. Some treatments can be a complete cure; others can greatly reduce the risk of arrhythmia recurrence.

Bradyarrhythmias (see chapter 10)

Bradyarrhythmias may be due to intrinsic disease of the cardiac conduction system or may be due to slowing of the heart through excessive reflex vagus nerve stimulation.

In bradyarrhythmias due to conduction tissue disease, it is important to:

- Ensure withdrawal of any drug that may cause a bradyarrhythmia.
- Exclude metabolic disturbances, such as hypothyroidism excluded.

Then, if the bradyarrhythmia persists, a pacemaker should be implanted.

In bradyarrhythmias due to excessive reflex vagus nerve stimulation patients generally have normal hearts and no cardiac conduction tissue disease. Children with reflex syncope should first be treated with drugs such as atropine. When considering a permanent pacemaker, specialist paediatric cardiological advice is required. Adults with reflex syncope will usually have trial(s) of drug therapy, e.g. midodrine, prior to pacemaker implantation. It is important to appreciate that:

- Only a small proportion of patients with reflex syncope will require pacing, (about 15%).
- A decision to use a pacemaker is best made based on the recording of spontaneous asystole with an implantable ECG loop recorder, - ILR.

Pacemaker Treatment (see chapter 12)

The main objectives of pacemaker therapy are to restore the patient to as near normal a lifestyle as possible and to reduce the risk of death (a secondary goal in many cases, as patients requiring pacemakers are often elderly).

Pacemakers are designed to:

- Raise the minimum heart rate.
- Relieve symptoms of bradyarrhythmia.
- Restore the physiological rate and sequence of electrical activation.

Modern pacemakers can usually increase the heart rate on exercise using built-in sensors (“rate-adaptive” pacing). Some pacemakers may also sense the body’s own demand for heart rate increase by using an atrial lead detecting activity from the atrium which is driven by the body’s natural pacemaker (dual-chamber pacing).

Modern pacemakers can restore atrioventricular synchrony, ensure that the atria to beat just before the ventricles, (dual chamber pacemakers) and thereby minimize the risk of creating the new symptoms of pacemaker syndrome.

Modern pacemakers will commonly improve prognosis and prolong useful high-quality life. They improve life expectancy from around 3 to 9 years in patients with high grade heart block. Pacing also reduces atrial fibrillation, stroke, heart failure and mortality in patients with/at risk of atrial fibrillation when the atrium is paced.

Double or Single Chamber Pacemakers?

Double chamber pacemakers (attached to the atrium **and** ventricle) are more costly to buy and more resource intensive to implant and to follow. However, they offer considerable flexibility and are very often more cost-effective than the "cheaper" alternative of a single camber pacemaker (attached to the atrium **or** ventricle). Single chamber pacemakers should be used in the ventricle when there is permanent atrial fibrillation and a slow heart rate and in the atrium when there is disease of the natural pacemaker but no evidence of block of conduction between the atrium and the ventricle. Pacemakers usually last for 8-12 years before their batteries are depleted.

Pacemaker implantation rates in the UK, (approximately 420/million) lag far behind the rates of implantation in Europe and the USA, (approximately 900/million).

Tachyarrhythmias

1) Atrial fibrillation (AF) (see chapter 16)

AF is the most common sustained tachyarrhythmia; its prevalence increases exponentially with age. This arrhythmia is associated with one third of strokes and with an increased risk of death and heart failure. AF is associated with a significant reduction in quality-of-life. AF consumes >1% of the total NHS budget.

The treatment of atrial fibrillation aims to:

- Identify and treat any underlying cause when present.
- Restore and maintain sinus rhythm (SR).
- Control the ventricular rate (pulse rate).
- Reduce risks associated with atrial fibrillation e.g., stroke.

The restoration and maintenance of SR can be partially achieved by using antiarrhythmic drugs although direct current (DC) cardioversion may be needed. Atrial pacing may reduce the likelihood of recurrent atrial fibrillation. Transcatheter or surgical ablation is highly effective at preventing both paroxysmal and persistent atrial fibrillation.

Ablation for AF can be achieved by percutaneous catheter techniques targeted at isolating the pulmonary veins combined with linear lesions to disrupt the atrial fibrillation substrate. Similar direct surgical ablation techniques can be implemented at when other cardiac surgery is being performed.

Heart rate control in AF can usually be accomplished by using AV nodal blocking drugs, e.g. digoxin, verapamil, b-blockers, or by catheter ablation of the AV node with pacemaker implantation to maintain an adequate ventricular rate.

Risk reduction in AF can be achieved by:

- Anticoagulation, since one third of strokes are associated with AF.
- Heart rate control which reduces the risk of heart failure.
- Effective restoration and maintenance of SR which may reduce the above risks.

Atrial fibrillation accounts for tens of thousands of admissions to hospital each year, is associated with one third of all strokes, and causes both a significant reduction in life-expectancy and a substantial increase in health-care costs across all age groups.

2) Paroxysmal Supraventricular Tachycardia (PSVT) (see chapter 14)

PSVT is a common condition in all age groups. It affects 350 new patients/million per year. A small proportion of patients are at risk of sudden cardiac death. Most patients have no other heart disease than the electrical fault that allows the tachycardia. Most of these arrhythmias can be completely cured using ablation techniques. Thus, curing PSVT may have a very significant impact on the quality of life.

Acute presentations are managed as follows:

- Recording and retaining an ECG, in close-collaboration with ambulance crews.
- Giving the patient a copy of the ECG.
- Attempting to stop the PSVT with physical/vagal manoeuvres.
- Referring resistant cases to the A&E department for acute management and all cases to cardiac electrophysiology for long-term management.

Management of patients presenting at the hospital acutely with PSVT is similar to the above except that intravenous drug treatment with adenosine or verapamil may be administered under ECG control (both monitoring and recording) and DC cardioversion can be administered if necessary. Most patients can be discharged when tachycardia has been terminated but some others should be kept in hospital for further evaluation. These include:

- Presence of Wolff-Parkinson-White (WPW) pattern.
- Severe haemodynamic compromise during tachycardia.
- DC cardioversion was needed.

These patients and most of those who can be successful discharged from hospital should be should be referred for specialist advice about the need for catheter ablation, especially when the WPW syndrome has been diagnosed.

Specialist consideration of patients with PSVT involves consideration of curative catheter ablation, and antiarrhythmic drug treatment for short-term management provided that there is no evidence of structural heart disease.

Long-term antiarrhythmic drug treatment can be considered in those few patients who cannot or are not willing to undergo catheter ablation. There are substantial concerns regarding the risks of antiarrhythmic drugs, which until the introduction of catheter ablation techniques were the mainstay of treatment, (see chapter 9).

PSVT occurs in about 2.25/1000 of the population, and accounts for a very significant impact on quality-of-life in many patients and a real risk of sudden death in a few. Many thousands of patients could benefit from simple curative catheter ablation techniques.

3) Ventricular Tachycardia (VT) (see chapter 18)

VT arises from the ventricles, results in a regular tachycardia and is usually associated with structural heart disease. It is potentially life-threatening.

For acute presentations outside hospital life-support measures may be needed and the patient should be referred as an emergency to the A&E department unless already assessed and under active management which includes a planned response to further attacks of the arrhythmia. It is essential to record and retain an ECG if practical.

The acute phase hospital management includes the following:

- Maintain life-support measures if needed.
- Record and retain an ECG.
- Restore sinus rhythm.
- Record a further ECG in sinus rhythm.
- Admit to a cardiac care unit with full monitoring, resuscitation and life support facilities.
- Refer to cardiologist/electrophysiologist.

Further management includes assessment for structural heart disease using echocardiography, cardiac catheterisation, cardiac magnetic resonance (CMR), computed tomography, and nuclear imaging as necessary. Most patients with VT and structural heart disease will have coronary heart disease and may need revascularisation.

Specialist management is essential for patients with VT:

- Most patients with VT and a structurally abnormal heart need ICD implantation.
- Antiarrhythmic treatment is not generally beneficial in patients with VT and a structurally abnormal heart.
- Patients with VT and structurally normal hearts usually do not need an ICD, but may be cured by catheter ablation.
- Patients with VF and a normal heart should usually receive an ICD, unlike patients with VT and a normal heart.
- Family screening and counselling is needed for patients with congenital syndromes.

Many patients who have had an episode of sudden cardiac death from which they have been resuscitated or who have had a heart attack in the past, or who are at high-risk due to inherited heart diseases, should be fully assessed to determine their need for ICD treatment.

MODELS OF CARE, DATA-COLLECTION AND SUPPORTING THE PATIENT JOURNEY IN HOSPITAL AND IN THE COMMUNITY

(see chapter 32, 35, 30 & 31)

Modern treatments for cardiac arrhythmias are highly effective and cost-effective. They compare very favourably with other heart treatments. In order to bring these treatments to those patients who need them, we need to educate patients and doctors and help them to understand a complex area of medicine. The results of treatments also need to be available to guide provision.

Models of Care (see chapter 32)

Modern effective treatments for cardiac arrhythmias need to be made much more widely available. Even basic cardiac pacing, in which the UK took an early lead 40 years ago, is now grossly underprovided in the UK compared to other Western European countries, and indeed recent UK implantation numbers are falling slightly.

Wherever possible, arrhythmia services should be provided as close to patients' homes as is practical. However, cardiac arrhythmia treatments represent a range of complexity, and some treatments can only be provided in a "tertiary" setting because of skill shortages or the need to cluster experience in the hands of a few doctors to ensure good outcomes. Providing treatments for urgent arrhythmia care in the hospital where a patient is admitted, rather than in another distant hospital, has great potential to reduce impact on bed-occupancy and wasted resources. However, some arrhythmia services can only be provided by inter-hospital transfer.

Permanent cardiac pacing has been available for over 40 years, is taught to all cardiology trainees, and should now be made available to patients in all DGHs. Providing permanent cardiac pacing and follow-up clinics in every DGH is a major challenge for staffing and other resources, but offers good dividends for patients and cost-efficacy.

The Fifth Joint Report of the British Cardiac Society and the Royal College of Physicians (2001) proposes that many arrhythmias services should move into DGHs, close to where patients live and work. Such services include complex device therapy such as ICDs and cardiac resynchronisation therapy with biventricular pacing. Complex device therapy can be provided in DGHs, and must always be built upon the foundation of an established permanent pacing service that will provide the basic medical and technical skills needed to achieve good results.

Cardiologists within or near conurbations may develop shared facilities with other local DGHs so that more complex device therapy can be delivered on a 'sector' basis and allow the clustering of implantation and follow-up skills, specialist nursing and other support, and also achieve economies of scale

Skills in diagnostic and therapeutic cardiac electrophysiology and catheter ablation are very scarce in the UK. The latest UK CCAD database returns suggests that only about 40 hospitals in the UK can provide these services, and only 16 of these achieve more than 100 cases per annum. In the UK there are about 65 consultants with a particular interest in cardiac arrhythmias. In contrast, in the USA there are 2,400 full-time or part-time cardiac electrophysiologists. In the UK about 600 such specialists are needed. Available data suggests that Western Europe and the USA can provide approximately ten fold the number of catheter ablation procedures than are possible in the UK. Catheter ablation is often completely curative, and should be made much more available in the UK.

Skilled cardiac clinical physiologists are also very scarce, and a major workforce initiative is needed, with resources, proper audit and regular performance review.

Patients with blackouts are often very poorly managed, and current acute medical admission audits are beginning to bring this to light. Blackouts, along with other arrhythmias, feature in the top 10 causes for hospital admission. They are a major source of re-admission because of difficulties with arriving at a correct diagnosis and providing definitive treatment. Misdiagnosis rates for epilepsy and falls are significant and costly. Blackouts management requires close collaboration across neurology, cardiology, falls clinics and neuropsychiatry. Currently national guidelines for epilepsy, falls and arrhythmias ***are being developed separately***, and this risks confusion and further waste and duplication.

Novel models of care, such as rapid-access specialist-nurse led blackouts triage clinics, have the potential to cut waste and achieve better outcomes. These should be trialled, carefully monitored and rolled-out across the NHS as indicated.

Sudden cardiac death in the young represents a major healthcare challenge and a substantial burden of grief for affected victims and families. About 400 children and young people suffer tragic unexplained death each year in the UK. Determining the cause of such tragedies and trying to prevent further incidents requires a concerted collaborative effort. Screening for inherited causes of life-threatening arrhythmia and death in patients and their families needs the coordination of electrophysiologists, cardiomyopathy services and genetics across the NHS.

The resuscitated victims of these sudden tragedies, and their relatives, need an explanation of these events to help the grieving and/ or recovery processes. Pathology services with expertise to perform detailed analysis of heart muscle and other tissues in such cases are very sparse in ten UK. Pathology services for victims of sudden cardiac death in the young should be developed in accordance with a national strategy across the NHS.

Data-collection and Audit (see chapter 35)

Data-collection and audit in a busy healthcare setting is difficult, time-consuming and complex. However, without good data, activity levels cannot be assessed, access to care cannot be determined, and outcomes of care cannot be demonstrated. A major information initiative is on-going through the National Programme for IT, (NpfIT), supported by significant new resources.

Clinical databases have consistently been shown to fail if they are top-down and management driven, and consistently succeed if they are bottom-up and clinician driven. Clinicians involved in arrhythmia care must be motivated and engaged in data-collection to give an accurate assessment of work load, treatment choices, and clinical outcomes.

Trusts must support IT involvement for clinicians involved in arrhythmia care. Some clinicians may be able to contribute IT skills, others will need back-up with data-clerks at the point of service-delivery. Some National Societies such as the British Cardiac Society and the British Cardiac Intervention Society and British Pacing and Electrophysiology Group have excellent experience in data-collection, assimilation and presentation. However data collection must be improved, particular in the arena of cardiac arrhythmias. High quality databases of cardiac ablation and atrial fibrillation are urgently needed.

Supporting Arrhythmia Patients in Hospital and in the Community.

Electrophysiology Centres (see chapter 30)

Cardiac arrhythmias range from being an uncomfortable nuisance to causing the sudden unheralded death of a child. Whatever the severity of an arrhythmia, patients and relatives are often frightened, and need time and accurate information to come to grips with the very complex concepts that even doctors may struggle to understand.

Medical time is very scarce, especially the time of a cardiac electrophysiologist because there are so few in the United Kingdom. Electrophysiology nurse specialists can be recruited for pre-admission clinics, simple services such as cardioversion, ICD follow-up activities, rehabilitation of ICD and arrhythmia patients and to assist provision of out-of-hours support. Such nurses can often give patient and families the support they need at times of distress. They are probably not routinely required for pacemaker services.

Out-of-hours cover for complex devices and arrhythmias is important, and is available only on a patchy basis. This applies to both nursing and medical cover. Provision of out-of-hours nursing, technical and medical support, especially for ICD patients, will reduce admissions to hospital, particularly after a device discharge, and is potentially cost effective.

All centres involved in provision of arrhythmia services should recruit specialist nurse(s) to support their activities, since they provide quality care and may greatly reduce costs. At least one nurse/clinical electrophysiologist is needed for each service that provides ICD patient follow-up, and additional nurses will be needed in larger centres.

Cardiac electrophysiology and device therapy is a complex area with rapid development. Many patients now have an ICD, on-gojng arrhythmia problems and heart failure. This group of highly complex, often very sick, patients will expand further. General and interventional cardiologists cannot be expected to master the detail required to provide skills for every arrhythmia problem, and should not have to assess such complex patients afresh out-of-hours for the first time because there is no electrophysiology on-call rota provided at consultant level. Cardiac electrophysiologists in centres or localities must establish specialist arrhythmia advice rotas for out-of-hours care to avoid inappropriate care and reduce the onus on non-electrophysiologists to make complex decisions outside their remit. These rotas will also support cardiac technicians and nurses in out-of-hours care-provision.

Patient Support Groups (see chapter 31)

Patients and their families with arrhythmias in the community may not know what they are experiencing, but only have the distress of their symptoms or of a sudden bereavement. Such patients need time, information and empathy.

The UK is fortunate to have both a very well-developed charitable sector in healthcare, and many gifted, dedicated and unswerving personalities who are driven to provide better support for others, often when they have suffered themselves directly or through their families.
Charities and independent bodies working in support of patients and families affected by arrhythmias now require Government support and funding to firmly establish their remit to provide clinical information and explanations, contacts and lobbying to get the best arrhythmia care from the NHS.

THE NECESSARY EXPANSION OF ARRHYTHMIA SERVICES AND & TRAINING THE NEXT GENERATION

(see chapter 33 & 34)

The timely expansion of modern arrhythmia care equally to all NHS patients will be greatly affected by workforce constraints. A 10-year plan (approximately) will be needed to address the marked shortfall in arrhythmia care in the UK compared to Western Europe. During the first three years immediate changes must be made to working practices in order to deliver more and better care, without the ability to much increase workforce numbers. For example, district general hospital cardiologists are currently required to contribute to unselected acute medical duties. Removing these responsibilities would leave room to increase the provision of pacing services in the UK towards those achieved in other countries.

In the following years more cardiology trainees should be encouraged to develop an interest in the management of arrhythmias and begin to emerge from training programmes. Previously such interest has been suppressed by the heavy focus on revascularisation to the exclusion of arrhythmia care. Trainee cardiologists have not understood the future of arrhythmology when planning their careers. Training bodies, Deaneries and trainers need to be given clear guidance about the need to emphasise arrhythmia training. Training schemes for doctors should be developed that allow for basic training in electrophysiology, blackouts and devices over one year of a 6-year course, with a further two year period of advanced training in arrhythmia care for those who will take a major interest in the area.

During these years newly qualified cardiac technicians should emerge if recruitment and retention in arrhythmia care is emphasised in the forthcoming National Service Framework document. The establishment of consultant-grade technicians may accelerate this progress by providing motivation and encouragement. Similarly it is anticipate that newly qualified electrophysiology nurse specialists should be trained and establishing consultant-grade specialist-nurses will accelerate progress by providing motivation and encouragement.

In the later years newly qualified consultant cardiac electrophysiologists will complete their training.

The 10-year plan allows the electrophysiological community time to aspire to, and plan for, standards of care that already exist in some parts of Western Europe and the USA. In a rapidly evolving area of cardiology, there are already standards decreed by randomised-controlled trial data that we cannot hope to meet in the UK quickly. For example, even if sufficient funds were made available to treat the 800/million patients at risk of sudden cardiac death after myocardial infarction, that the trial-data suggest may be eligible, this could not be achieved without elective waiting lists of many years. During their wait, patients would be all too aware of the risks they faced.

During these years of development, patients will continue to be at risk of sudden cardiac death. However, by planning and implementing steady growth towards the 10-year targets, and continuing to select patients on the basis of greatest need, the arrhythmia community and the National Health Service can hope to provide the quality and quantity of care needed.