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Cardiac Risk in the Young (Screening) Bill
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Speeches and interventions by:
Ms Dari Taylor (Stockton, South)
David Wright (Telford)
Mr. Eric Pickles (Brentwood and Ongar)
Mr. David Stewart (Inverness, East, Nairn and Lochaber)
Dr. Ashok Kumar (Middlesbrough, South and Cleveland, East)
Mr. Kevan Jones (North Durham)
Tim Loughton (East Worthing and Shoreham)
Ms Meg Munn (Sheffield, Heeley)
Miss Anne Begg (Aberdeen, South)
Mr. Nigel Jones (Cheltenham)
Dr. Julian Lewis (New Forest, East)
Mr. Martin Caton (Gower)
Huw Irranca-Davies (Ogmore)
Dr. Andrew Murrison (Westbury)
The Parliamentary Under-Secretary of State for Health
(Miss Melanie Johnson)

9.33 am

Ms Dari Taylor (Stockton, South) (Lab): I feel privileged to have the opportunity to bring my Bill to the Floor of the House for the consideration of Members and Ministers from the Department of Health. I realise that I am lucky to have secured the fifth position on the private Members' Bills list. Many Members have congratulated me, wished my Bill good passage and told me how lucky I am. Many have been in the House for 20 years and more yet have never surfaced in the selection process, despite their reputation and considerable knowledge of specific policy areas. It is indeed a privilege to have the opportunity to put on the record the fact of sudden death in the young, and the medical knowledge and experience that could—and I believe should—inform medical practice through screening.

The short title of my Bill is Cardiac Risk in the Young (Screening). Its substance refers to the tragedy of sudden death in the young from a variety of cardiac problems. If diagnosis of the condition had taken place—the condition is clearly visible through screening and its symptoms are known—its potential to be fatal would have been recognised by a cardiac specialist. A different lifestyle, drug support, a small surgical operation known as an ablation, or the fitting of an implantable cardioverter defibrillator device could have been suggested and might have resulted in a life being saved.

Before I outline the detail of the Bill, I should say why its substance—the knowledge and experience of cardiac specialists and their research teams that in some cases inform the medical response to sudden death—is important to me. The inspiration for the Bill was a tragedy. Two years ago, just after new year, the son of a very close friend of mine died. Levon Morland was 22 years old—young, athletic, a keen sportsperson, in a demanding job, and showing no sign of a health problem that could be fatal. In fact, Levon and his family knew that he had a heart condition: Wolfe-Parkinson-White syndrome. He had been screened and had visited a cardiac specialist. An operation to correct his condition was available, but it was nasty, so as the specialist suggested that his condition was no more than a nuisance, Levon was more than keen to just get on with his life. He no longer has a life to get on with. Levon's parents, Jeff and Sandra Morland—a friend to many in the House—his twin brother and the rest of the family were and remain grief-stricken. They never stop feeling guilty, saying again and again, "What if? What if we'd done . . .?" The critical fact for me and for the Bill is that it was not up to them to do anything. The potentially fatal condition should have been clearly and factually explained. A lifestyle package of drug support, radiofrequency ablation or a pacemaker—various treatments could have been prescribed to control the problem or reduce the risk. Levon's first-degree relatives should have been given a clear understanding of the nature of his condition. As it was genetic in his case, they too were at risk. He should have been reassured that all that could be done medically was being done. He should have been led to understand that even without warning symptoms, Wolfe-Parkinson-White syndrome could be fatal.

David Wright (Telford) (Lab): One of the tragedies is that the treatment for the condition can be carried out quickly. Does my hon. Friend agree, therefore, that it is very sad that the problem was not identified and dealt with speedily?

Ms Taylor: My hon. Friend's intervention is timely. From the symptoms and the diagnosis, it is clear that treatment should have been undertaken. My young friend should never have been told, "It's a bit of a nuisance. Get on with your life." My hon. Friend is right—the treatment is quickly put in place, and should have been done.

Levon Morland should have been able to understand and to accept that, even with full medical support, his condition could be fatal—he should have been left under no illusion. Because I know the family, I know that no such advice was given. Levon was merely told, "Your condition is a bit of a nuisance. Get on with your life."

Mr. Eric Pickles (Brentwood and Ongar) (Con): As the hon. Member for Telford (David Wright) said, Wolfe-Parkinson-White syndrome is relatively easy to treat. However, in a case in my constituency the family of a toddler who was diagnosed with the condition were told that it was a relatively common condition, and that although it would be a bit of a nuisance everything would be okay. Everything was not okay. That demonstrates the importance of the hon. Lady's Bill in relation not only to screening, but to increasing understanding among the medical profession.

Ms Taylor: I thank the hon. Gentleman for that intervention. It is crucial to have an educative process. I do not want to find the established heart community disputing the clear evidence that too many hon. Members will present to the House today.

Mr. David Stewart (Inverness, East, Nairn and Lochaber) (Lab): Does my hon. Friend agree that although screening is a vital tool, it is not suitable for the whole population, but should be aimed at high-risk groups?

Ms Taylor: My hon. Friend is absolutely right. Repeated electrocardiogram screening can be an expensive procedure, and that has to be controlled. It is equally important, of course, that if an inherited condition exists, families—first-degree relations—should have the opportunity to be screened. The Bill does not ask for a national screening programme, but many countries have those for young people at different stages of their lives and for families with potentially fatal conditions.

Levon Morland received a diagnosis statement from a professional cardiac specialist. I want to ensure that such a casual and uninformed statement about a life-threatening—in Levon's case, life-taking—condition can never be made again. Levon's death has left a mark on our community in the north-east. We all want to support the Morland family because we know that the pain of his death will not go away. The best support that we could give—I press this on the Minister—is to ensure that full and effective medical treatment is provided. I hope that the Government will acknowledge that and deliver it.

If that untimely death was not bad enough, and it was, I was soon afterwards told of the death of another young man in my region—a 19-year-old from Redcar who died suddenly while out enjoying himself with friends after a day on the golf course. Ian Bowen, who lived with his parents Maralyn and Kenny, died from Wolfe-Parkinson-White syndrome that had been diagnosed but not treated. Ian suffered from an additional electrical connection between the atriums and ventricles of the heart. He had been diagnosed with the condition and had regularly consulted his cardiologist, but was repeatedly reassured that it was not serious, would not affect his life, and was nothing

to worry about. He died suddenly just 10 months after visiting the doctor complaining of feeling his heart racing. One can imagine his family's complete shock and utter devastation.

My hon. and learned Friend the Member for Redcar (Vera Baird) is unable to be in the House today, but asked me to express her support for my Bill, to press the Government for a positive response, and to emphasise the belief that all people should receive the best medical service available and should never be left wondering, "Was there anything else that could have been done?" She sends her sympathy to the Bowen family, who live in her constituency.

My hon. Friend the Member for Monmouth (Mr. Edwards) is also unable to be here, but wrote to me about his constituents, Mr. and Mrs. Berzolla, whose case has persuaded him to support the Bill.

I have mentioned the concern, sympathy and support of two hon. Members. I had to stop other colleagues giving me additional comments to pass on because there were so many. I decided that that it would be sufficient to mention two and to assure the House that there are many more.

After that tragedy upon tragedy, I soon became aware of the number of deaths that have occurred. Such tragedies do not happen only in Britain, but in other parts of the world, including Europe; we constantly see them reported in the press. Cardiac Risk in the Young has produced a very able and academically organised booklet that outlines the scale of the problem. We are talking about four deaths a week.

Dr. Ashok Kumar (Middlesbrough, South and Cleveland, East) (Lab): How accurate are the assessments of how many people die from the disease per week? Are we sure that it is so many, or is it guesswork?

Ms Taylor: The figure of four is no more than a best guess that comes from pathologists' reports. Unfortunately, many sudden deaths that do not involve accident or suicide end up being recorded as death from cardiac failure or from natural causes. I press my hon. Friend the Minister to accept that better analysis of cause of death is required to provide an accurate picture.

Mr. Kevan Jones (North Durham) (Lab): Is it not also the case that many such deaths are put down to accidents? For example, many fit and healthy teenagers who die in swimming pools have their deaths put down to drowning, but the real cause is a heart condition.

Ms Taylor: That is absolutely correct. Many youngsters' conditions remain undiagnosed, although they have presented symptoms to general practitioners. They are sent away with the statement, "You are probably suffering from stress", "It could be depression", or "It may be asthma." That is a serious problem. Although the symptoms are well documented academically, they are not generally known to GPs.

Mr. David Stewart: On a similar subject, does my hon. Friend agree with the analysis in the magazine, "Heart", which suggested that 80 per cent. of deaths among athletes follow vigorous exercise?

Ms Taylor: Many hon. Friends are demonstrating their knowledge of the problems. That is right: the young people involved are often keen athletes who are putting a strain on their heart. They have shown symptoms that, sadly, were undiagnosed. They could still be competent athletes—some have Olympic potential. They require control mechanisms so that they live to enjoy their athleticism. Sadly, that does not happen.

I want to mention some people who died suddenly without necessarily receiving a diagnosis to explain the reason for their deaths. I shall begin with some of the stars of the world. The Hungarian footballer Miklos Feher played for Benfica in Portugal and died at the age of 24. A Georgian football player died in his sleep. He was 23 and had shown no sign of illness. Later, he was found to have suffered from a cardiomyopathy. The same condition killed the Cameroon international football player, Marc-Vivien Foe, and Terry Yorath's young son, Daniel. Those are high profile cases, which show that young, apparently fit people throughout Europe as well as Britain suffer from the tragic fate that we are discussing. All those cases presented comparable characteristics.

Tim Loughton (East Worthing and Shoreham) (Con): I hope that my intervention is not untimely. It is on a related subject. The hon. Lady is making a forceful speech, as she did when she addressed Cardiac Risk in the Young—CRY—earlier this week.

Constituents of mine lost a 17-year-old son from sudden arrhythmic death syndrome only a few weeks ago. A fit teenager suddenly died. My constituents were subject to a police investigation because of the sudden nature of the death. It is bad enough to lose a child out of the blue, but it is doubly distressing to be subject to investigation, albeit for understandable reasons. Will the hon. Lady take on board that other aspects need to be considered and that parents who have suffered a terrible tragedy and have the blow compounded need to be treated more sensitively?

Hon. Members: Hear, hear.

Ms Taylor: The House has responded to the hon. Gentleman. Unfortunately, the circumstances that he mentioned are replicated time and again. When a young person dies, the immediate thought is, "Was there drug abuse? Were the parents involved?" That is an outrage. Sadly, that occurs even when symptoms that suggested a condition were left undiagnosed. I shall stress that continually. Again, the hon. Gentleman made a timely intervention.

We are considering young, athletic people who die suddenly, sometimes with little or no medical warning. There is often no prescribed medical treatment and no acknowledgement that the disease that killed a young person is genetically inherited. According to the coroner, the majority die of cardiac failure—natural causes. That is unacceptable.

Ms Meg Munn (Sheffield, Heeley) (Lab/Co-op): Later, I hope to have the opportunity to talk about a constituent who has a specific heart condition. There appears to be a range of heart conditions that can lead to sudden death. Will my hon. Friend cover that point? The issue is especially complex because not only one heart condition is involved, and the affected families could suffer from a range of conditions that could be difficult to detect.

Ms Taylor: My hon. Friend has anticipated a part of my speech. Of course, I shall respond to that point in detail as I progress.

To emphasise the importance of the issue, I point out that *The Independent*, *The Mail on Sunday*, the *Daily Mail*, *The Daily Telegraph* and the *Daily Mirror* often produce reports that outline the problem of heart defects that strike the young and the fit. It is a common theme of many of the articles that I have read. I suggest to my hon. Friend the Minister that if such cases are reported again and again, one would like to believe that the medical fraternity recognises the problem and begins to accept that there must be better and different solutions. The Bill would introduce screening procedures that would help to prevent sudden death.

I have mentioned some of the stars who suffered sudden death and I should now like to refer to some cases of the stars in our homes who have been affected. Ewan Bellamy was 31. He was returning from New Zealand with his pregnant wife when he suffered sudden death. His family requested that its members should be referred to a specialist for screening. The local national health service trust denied the request.

Ellis Curran, a fit and healthy 28-year-old, had shown symptoms. He died in his wife's arms after playing with his children. Tests showed that he suffered from a hypertrophic cardiomyopathy—an inherited condition that is well known and well documented throughout the medical profession. He showed symptoms but received no treatment. Earlier, I mentioned Marc-Vivien Foe, who had shown clear symptoms, including chest pains that were more severe than would ordinarily be expected. The condition was undiagnosed, and the post mortem showed that he died from hypertrophic cardiomyopathy.

Joanne Fotheringham was 24 and lived in the Western Isles. She went to bed and never woke up. A statement said that she died from an undetected heart condition. With all our medical competence, do we seriously accept that an academically well-documented medical condition should go undetected?

Alison Linforth was a bright and sparky 16-year-old from Birmingham. On the first day of her A-level course, she sat down and died at her desk. The pathologist told her family that she had died of Long QT syndrome. The coroner's verdict was natural causes. That is unacceptable. She had complained of chest pains but they were not investigated.

Lisa Harley was a 27-year-old nurse. She had complained of tiredness and fainting, which is closely associated with a potentially fatal condition. She was diagnosed with depression and died of a heart condition. We all know from medical evidence that an implantable cardio defibrillator could have saved her life. After her death, the family insisted on screening for the rest of its members. Her sister was diagnosed with Long QT syndrome. She was fitted with an ICD. Her heart stopped last October but the device kicked it back into action.

Several doctors dismissed Alex Edwards's symptoms. He was a 12-year-old promising young cricketer. His problem was undiagnosed. Laura Moss was 13 and a national swimmer, who was tipped as a future Olympic champion. She died at the poolside, watched by 200 school friends. Her parents watched the young female from Weymouth die. Youngsters are showing symptoms of potentially killer diseases. Again and again, the medical profession does not diagnose or respond to them.

Miss Anne Begg (Aberdeen, South) (Lab): Obviously, in many cases the symptoms were not picked up. As general practitioners are in the front line of the medical profession, does the Bill contain anything that will help them to pick up the symptoms to do the necessary screening and ensure that the proper treatment is provided?

Ms Taylor: I can respond positively to my hon. Friend. Clause 1 clearly identifies how crucial GPs are in the train of diagnosis to preventing or defining a potential problem. In relation to that, the proposal in the Bill is that the conditions that we know to be tied into potentially fatal diseases should be clearly chronicled so that general practitioners are able to understand what a young person might be suffering from. So, yes, the Bill responds to the problem that my hon. Friend has just outlined.

Dr. Brian Iddon (Bolton, South-East) (Lab): I congratulate my hon. Friend on highlighting the fact that there are many preventable deaths among young and older people. It has been well known for a long time that approximately one in five Down's syndrome babies are born with a heart defect, but until just a few years ago there was no routing screening of such babies, either at birth or shortly afterwards. As a result, many of them died in the early years of their life. Will my hon. Friend join me in congratulating the Down's Syndrome Association for highlighting these problems? I, in turn, would like to congratulate the charity Cardiac Risk in the Young—CRY—on stimulating the introduction of this Bill through my hon. Friend. Does this not illustrate the important role that charities play in bringing relatively unknown problems to the Floor of the House, which can result in the saving of quite a few lives?

Ms Taylor: Yes, those charities make an excellent contribution. I am only too pleased to be associated with all the work that the Down's Syndrome Association has done. I hope that my charity, Cardiac Risk in the Young, will be equally successful. We are here to try to persuade the Minister that we should be recognised.

I shall return to the examples that I was giving to the House. David Staff, aged 17, who lived in Blackburn, the constituency of my right hon. Friend the Foreign Secretary, was found to have suffered from hypertrophic cardiomyopathy. He was a runner and his father was the marshal of the race that he was taking part in when he died. These are cruel details, but hon. Members must try to get their head around them. Christiaan Smith, aged 24, from the Gower constituency, was told that he was suffering from flu symptoms. A few days later, he was found slumped at the bottom of the stairs. His mum, Pauline, said:

"Our buoyant, effervescent son, so full of life, had died from a condition called myocarditis."

The question must be asked: why was that condition not diagnosed earlier, and if treatment was feasible, why was none put in place?

David Elliot, aged 24, lived in the constituency of my right hon. Friend the Prime Minister. This young man was an international triathlete. He died from an undiagnosed heart condition. His sons are now receiving periodic testing from a special paediatric cardiologist, and they will continue to do so until they are 20 years old, so I am delighted to be able to say that something positive has come from the tragedy in the Elliot family. Jim Lorrimer watched his sister's daughter die from hypertrophic cardiomyopathy, an inherited condition that nobody thought could impact on other members of the family. He then watched his 25-year-old son die from the same condition.

I could go on to list many more young people who have died. They were usually athletic, and many died from a hypertrophic cardiomyopathy, which is clearly detectable by screening. Their symptoms were regularly ignored, and neither they nor their first-degree relatives were tested.

Mr. Alan Campbell (Tynemouth) (Lab): My hon. Friend has listed a number of cases, each one a tragedy in its own right. If I understood her correctly, the age range of the people involved was between 12 and 31. Can she tell us how she defines a "young person"?

Ms Taylor: I am not in line to define what a young person is. I think that I am pretty young at 60, frankly. [Hon. Members: " Hear, hear!"] Thank you very much. I appreciate that warm and welcome—and, of course, accurate—response. The medical profession defines people under 35 as young. Because they are young, and especially if they are in their teens or early 20s, it is assumed to be improbable that they could have a serious heart condition. That is the message that I hope to transmit to the House today.

I could outline many cases to the House; all of them are tragedies. They often involve people who were athletic, and whose condition was either undiagnosed or misdiagnosed. In many cases, no treatment was given. The condition is often inherited, but many first-degree relatives do not receive an invitation to be screened and therefore remain unaware that they might have a fatal condition.

Each death sends shock waves round a community. The positive response to the Bill has been widespread. Relatives and friends are desperate to make sure that no one else has to suffer the sudden death of a loved one. I pay tribute to the dozens of relatives and friends who have campaigned for action. Many, if not all, are active in the charity Cardiac Risk in the Young, a body that has focused attention on this issue, organised research, lobbied Members of Parliament and provided central support to the achievement of the Bill. It has been, in part, the inspiration for today's debate. Many of the people involved have written to their Members of Parliament, to the Secretary of State for Health, to the Minister herself, and to the Prime Minister, to say how desperate they are for the Government to support the provisions in the Bill.

The all-party group on cardiac risk in the young has been outstanding. It has publicised the Bill to families through newsletters and through its website. Even the YMCA, which I managed to contact through my close friend, Councillor Louise Farthing, has taken up the initiative through its parliamentary officer, Rob Smith. It has sent out updates in its newsletter, "In Touch", and many of its members have written in. The response to the requests from the YMCA has been very positive. As I have said, newspapers cover the problem in ways that are distinct to their readership, and there are many examples of newspapers stating—perhaps implicitly, rather than explicitly—that a young person's death from an undiagnosed cardiac condition is an indictment of the medical profession. The campaigning has been widespread, because the impact of sudden death in the young is so widespread.

I am pleased that the Bill has received the support of nearly 100 Members of Parliament, all of whom were prepared to say their piece today. I am absolutely delighted that so many colleagues from both sides of the House are here. I have also received positive comments from the Chairman of the Health Committee, my hon. Friend the Member for Wakefield (Mr. Hinchliffe), who has wished the Bill every success. He has supported its passage and kindly given his advice. He has also promised me that if the Government respond positively to the Bill, he will persuade the Health Committee to carry out an investigation into cardiac risk in the young. He will also carry out an investigation into how the medical community responds to the problem. I would like to thank him for that incredibly positive offer.

Last Wednesday, a parliamentary reception filled the Terrace dining room. More than 200 people attended, including more than 50 Members of Parliament. There were positive speeches from the Minister of State, Department of Health, my right hon. Friend the Member for Barrow and Furness (Mr. Hutton), the shadow Minister for Health, the hon. Member for East Worthing and Shoreham (Tim Loughton), the ITV sports presenter, Jim Rosenthal, the chair of CRY, Greg Whyte, and the founder and chief executive of CRY, Alison Cox. They all made powerful and interesting speeches. Of course, I was persuaded to speak for two minutes, which I did, as I never want to take a liberty.

Tim Loughton: It was a long two minutes.

Ms Taylor: We should not be picky over time.

I want to reassure the House that the Bill references two factors: the typical medical response to symptoms that suggest a potentially fatal condition, and the known and proven value of screening that prevents conditions resulting in fatality. From the research and experience of a small number of highly qualified specialist cardiologists, knowledge of the diseases that can cause sudden death is available and has been published in reputable journals. That provokes me to ask the question: if this knowledge is available, why is it not used to inform medical diagnosis and prescribe medical responses?

A desired procedure exists that can respond to problems that can cause sudden death. First, when an individual presents early symptoms to a GP, which could include fainting, disproportionate breathlessness or palpitations, he or she should be referred for screening to a relevant cardiac specialist. Secondly, the specialist, who would have detailed knowledge of cardiomyopathies, ion channelopathies and other conditions listed in the Bill, would perform the screening and pick up those conditions. He would be able to see an extended QT interval for Long QT syndrome, or an enlarged myocardial wall for hypertrophic cardiomyopathy. With careful and expert involvement in diagnosis, such definable problems will be seen using a straightforward screening procedure. Thirdly, a patient's first-degree relatives would be involved, so that they understand that the disease has a genetic relationship to the rest of the family. Clearly, these diseases are life-threatening, and such an inherited condition should be understood by family members.

Tim Loughton: On the last point about inherited disorders, will the hon. Lady acknowledge that a particular problem exists in relation to looked-after and adopted children, in which both she and I have a particular interest? It is incumbent on those involved to pass on medical records for children placed in care, and to make available to the relevant authorities the records of the birth parents of adopted children.

Ms Taylor: Again, that is an excellent contribution. The hon. Gentleman speaks to my heart, as I am sure that he realises that my daughter is adopted. We have a full medical record of her family, and we understand exactly what conditions could have impacted on her. Of course, my daughter also knows her natural family, which makes that relationship so much easier. It was a worthwhile intervention.

The conditions outlined in the Bill are rare—I have no problem in admitting that. I also have no problem in stating that invariably cardiac specialists are used to examining a different generation of people with different heart problems. That is one of the problem areas—because their surgeries are chock-a-block with the over-40s and over-50s, sadly, they are missing telltale signs. While screening is simple and cheap, it also requires a relevant specialist who has an understanding of cardiomyopathies and ion channelopathies, and such specialists, who know what they are looking for, must be given the opportunity to look for those conditions when symptoms suggest that they exist.

David Wright: My hon. Friend mentioned earlier what was happening across the rest of Europe, and it would be helpful if she could say whether more comprehensive screening is available in other countries. I understand that that is the case in Italy, and we may be falling behind some of our European partners.

Ms Taylor: My hon. Friend is again correct. I do not have complete knowledge of the availability of universal and national screening programmes throughout the world. I shall refer to that later in my speech, however, with regard to New Zealand.

To illustrate this point about using a specialist who has expert knowledge, who has researched this area and who is aware of the often small and incredibly detailed tell-tale signs, I ask the House to think of the emotional shockwaves when a young person dies after having been told that their echocardiogram was clear, when in fact it was not. Echocardiograms are kept—they can be looked at again—and in such cases, when the echocardiogram has been looked at again, it has been clear that there was a problem. I ask the House: how on earth can a family live with the knowledge that the echocardiogram screening process took place, and the medic missed the problem? I am sure that everyone will understand that that is a living hell for the family, but I suggest to the House that the cardiologist who looked at that echocardiogram would also have found it incredibly difficult to live with himself afterwards.

With the best screening practice, the cardiologist would spot the problem, as they know what they must look out for. I spoke earlier about my good friend who was told, "Get on with your life, this heart problem is no more than a nuisance." We now know that the nuisance killed him—he has no life to get on with. The Bill requests that specialist cardiologists are involved in this screening process, and that they must inform patients of the seriousness of their conditions. Patients must then have the opportunity to make decisions that reflect how and in what way they accept or reject that advice.

With best practice, the relatives would also be invited for screening. I want to illustrate that statement. Not only do we know that the condition is inherited, we also know what is the probability of risk: a child has a 50:50 chance of inheriting a disease listed in this Bill if their parents have it. I have been told again and again, however—and it is documented—that in the specific case it was not until the fourth death occurred that anybody thought to screen the rest of the family. The fact that first-degree relatives have a 50 per cent. chance of inheriting the condition means that screening is vital, not only when someone is diagnosed but after a sudden death when there was no diagnosis. Families who have seen siblings or parents die need to be told of the actual cause of that death, and the potential risks to them and the rest of the family. Too often, they are not—the coroner's report records that the death was by natural causes. It is crucial that a knowledgeable pathologist with relevant training determines the cause of death. On many occasions, families have had to fight to get that information, which is totally unacceptable.

I want to talk about each of those problems in more detail. Before doing so, however, let me say that in many cases the cause of most distress is also the cause of greatest hope. If we understand and know where the gap in service is, and we understand that by filling that gap we have a chance to prevent deaths in future, we must surely see this debate as a moment for optimism. We can do something about it. We can find the individuals at risk, treat them and enable them to manage a significantly lower level of risk. Perhaps we can even eliminate the risk altogether.

There are problems to which there are no solutions. I shall be analysing the problems and, where they exist, the solutions, and explaining how the Bill could plug some of the most important gaps.

I see the first hurdle as the point of diagnosis—diagnosis by a GP who must not shy away from the knowledge that certain symptoms can constitute a warning of a potentially fatal condition, no matter how young and otherwise healthy someone is. Diagnosis is not difficult if the doctor knows what he is looking for. There are often obvious warning signs: palpitations, shortness of breath, fainting or chest pains. All too frequently, however, they are dismissed.

Let me quote from research by Alison Cox, founder and chief executive of Cardiac Risk in the Young. She writes

> "From the personal evidence given to CRY, when a person of 16 years of age presents themselves to a GP surgery or an A and E department, the medics think there can't be anything wrong and they are dismissed. If you have the same symptoms at 60 you are put straight into cardiology. It's ageism in reverse".

Once the GP has realised the potential seriousness that can normally be picked up by an electrocardiogram or an echocardiogram, that should be his concern. He should explain what treatment opportunity there is, and ensure that it is available to a young person.

An electrocardiogram, or ECG, is commonly used. It is a non-invasive procedure to examine electrical conduction pathways. It can determine the rate and regularity of the heartbeat, the size and position of the chambers, and whether there is any damage. An echocardiogram, or echo, shows muscle thickness and the size of the chambers by means of ultrasound. As well as providing one-dimensional images known as M-mode echo, allowing accurate measurement of the heart chambers, the echocardiogram offers far more sophisticated and advanced imaging. That is known as two-dimensional echo, and is capable of displaying a cross-sectional slice of the beating heart, including the chambers, the valves and the major blood vessels that emerge from the left and the right ventricle.

There are cases in which people have died apparently without cause, having been cleared by ECG and echo. Because both procedures are recorded, it is possible to take a look—and there, perfectly clear to those who know what they are looking for, are the tell-tale signs of the condition that killed those people. The problem lies not just with GPs but with cardiologists. I acknowledge that cardiologists are highly specialised and very capable, but it appears that in some cases they simply lack knowledge of this particular set of conditions, and do not see problems when presented with the results of an ECG.

I stress again that I am making no personal criticism of doctors. I do not want the medical establishment to take me on. I want the medical establishment to understand that what I am saying is academically detailed and uses practical evidence. I ask it to accept that a systematic problem exists: it is not any individual's fault. I realise that hardworking medics prioritise, and that their main clinics consist of people over 50. In such circumstances it is easy to underestimate the potential problem involved in a 20-year-old's heart condition. The Bill, which emphasises the connection between symptoms and screening by relevant cardiologists, should significantly reduce both the lack of screening and inadequate screening, as well as inadequate interpretation of the results. All those things are central to the cause of death.

Dr. Kumar: I listened carefully to what my hon. Friend said about doctors and the medical establishment. She is making a powerful case. People studying to become consultants and cardiologists may ignore the important factors that she has mentioned, or may be unaware of them. Could they not be included in the curriculum?

Ms Taylor: While I think my hon. Friend's intention is honourable, I think that politicians should be very cautious about telling professionals how to draw up their curricula. I can suggest and persuade, but it is up to those organisations to define appropriate training, and to ensure that medical practitioners in all spheres understand what they are doing.

We are talking about relevant cardiologists who have clear and specific knowledge of the problem, but are overwhelmed by the work that they are asked to do. That invariably means that they will underestimate the condition of a 20-year-old. I hope that there will be more understanding of the problem as a result of the Bill, and the education process that all of us, not just medics, are undergoing.

The second hurdle involves treatment. The belief that it is not just a question of the symptoms of confirmed conditions but of treatments that do not exist is nonsensical. People have complained that screening cannot be effective because the condition is unidentifiable. As I have tried to prove today, certain highly specialised cardiologists would not agree with that. It simply is not true. While I acknowledge that there is no cure for some conditions, there are treatments that can alleviate or control them, and possibly reduce the risk of death.

There are drugs such as beta blockers, which block the effects of adrenaline on the body's beta receptors. They slow the nerve impulse and travel to the heart. As a result the heart does not have to work so hard, because it needs less blood and oxygen. Beta blockers are also the impulses that can cause arrhythmia. They are used in cases of hypertrophic cardiomyopathy, arrhythogenic right ventricular cardiomyopathy, Long QT syndrome and Marfan syndrome.

Diuretics—water tablets—can be used for dilated cardiomyopathy. It is believed that the young Irish footballer Cormac McAnallen died from dilated cardiomyopathy, but that was induced by a virus. That is very different from inheriting the condition. Diuretics rid the body of excessive fluid, and can be very effective in improving the performance of the heart.

There are the simple steps involved in surgery—normal ablations or excisions of the heart, or a catheter ablation, which involves the delivery of electrical energy via a catheter inserted in the groin and travelling to the right side of the heart where the arrhythmia originates. That creates a small scar which is incapable of transmitting any arrhythmia, and is used for arrhythogenic right ventricular cardiomyopathy.

Radio frequency ablation is carried out by passing a wire into the heart via the large artery in the leg—the femoral artery. The abnormal pathway is located by the electrical stimulation, and destroyed by passing a high current through it. That treatment can be, and is, used for Wolfe-Parkinson-White syndrome. Pacemakers and implantable cardioverter defibrillators—ICDs—are also used. In some patients with hypertrophic cardiomyopathy, pacemakers achieve a normal signal. Such a signal may fail, and a pacemaker is there to kick the heart back into action. In cases of rapid heartbeat that cannot be controlled by drugs, an ICD can be fitted, which is similar to pacemaker. A box is implanted under the skin in the upper chest. The box has fine wires that are attached to the heart to record and deliver electrical impulses, in the absence of normal electrical impulses. It is important that I make it clear that treatment is possible. It is crucially important for us all that the need for treatment be acknowledged, and that it be provided.

If the first problem is lack of diagnosis and the second the lack of treatment, the third is that there are no referrals for families in which such a disease can be inherited. Relatives are not invited for screening, yet three or more people in a single family can die because such conditions are inherited. How can relatives not be at risk when it is known that the disease is genetic? I am afraid that no response or explanation can suggest anything other than a lack of knowledge. I defer to my hon. Friend the Member for Middlesbrough, South and Cleveland, East (Dr. Kumar), who suggested that we consider the role of training in this regard. The Bill does not provide for that, but the information that I have received suggests a lack of knowledge on the part of medical practitioners. These conditions are rare, but they have been well researched and well documented in medical journals. Their rarity only underlines the importance of establishing specialists throughout the country, and of using the solutions that the Bill offers.

There are so many examples illustrating the gap in service provision that I cannot give them all, but I shall briefly outline one that presents both a problem and a solution. A woman named Sandra Pearce asked her GP for screening following the death of her daughter, and was told, "I shouldn't worry if I were you. These things are very rare." I accept that that is so, but they are not rare when the condition is part of an inherited gene. There is a 50 per cent. chance of inheriting such a disease, as I have explained. Her primary care trust turned down her request for testing. Her cousin had come over from New Zealand for the funeral, and on returning, she explained to friends why she had been away. Within 48 hours, her GP was on the phone, advising her to make arrangements for genetic testing. All of us want this medical service to be available in Britain. My Bill asks that this service be recognised, and all will agree that it must be delivered. It is clear that it has great potential for saving lives.

Academic research, and research based on practical experience involving actual medical activity, has been published in serious medical journals. It outlined the conditions that can cause fatality, the accompanying symptoms and the treatments that can alleviate the conditions and cut the risk of sudden death. The Bill is primarily concerned with screening as a process for diagnosing conditions, thus helping to prescribe medical solutions where they exist. However, for the House to understand the Bill's relevance, I need to outline the conditions and relate them to the value of screening.

Let us first consider the group of conditions that come under the heading of cardiomyopathies. Hypertrophic cardiomyopathy is the most common cause of sudden death in those aged under 30, and its prevalence in the general population is one in 500. Today, more than 10,000 people in the UK suffer from this problem. In a healthy heart, every beat results from an electrical signal that starts at the top and passes down through the heart. Hypertrophic cardiomyopathy is caused by an abnormality of the proteins responsible for the contraction of the heart. For reasons that are not clear, the abnormal proteins result in a thickening of the heart muscle, and predispose the sufferer to arrhythmias that can cause sudden death.

Hypertrophic cardiomyopathy is incurable but the symptoms can be ameliorated and sudden death is preventable. In the majority of cases, the condition is inherited from a defective gene in one of the parents. As I have said, there is a 50 per cent. chance that each child will have the disease if the parent presents the symptoms. Those symptoms are well known: shortness of breath, chest pains brought on by physical exertion, rapid palpitations and an irregular heartbeat, light-headedness and black-outs.

Treatments do exist, and although there is no cure for hypertrophic cardiomyopathy, screening enables treatment to prevent complications, reduce symptoms and prevent premature death. Treatments include drugs such as beta blockers, the use of an ICD to record and deliver electrical shocks in the presence of fatal heart rhythm disturbances, and in some cases surgery. Through a surgical myectomy, a portion of the thickened heart muscle is removed, and the widening the outflow tract in the left ventricle relieves obstruction.

Arrhythmogenic right ventricular cardiomyopathy, involving a progressive replacement of normal right ventricular muscle cells by fibrous tissue and fat, is the second most common cause of unexpected sudden death in the young. The condition is inherited; indeed, there is a 50 per cent. chance of inheriting the abnormal gene. Diagnosis, involving the use of an ECG and 2-D echo, can be problematic and usually requires a specialist with expert knowledge. The features are often very subtle, underlining the crucial role of cardiologists with the relevant specialism. So it is clear that screening can outline the problem and offer solutions.

I offer some startling facts about arrhythmogenic right ventricular cardiomyopathy. Typical symptoms include rapid heartbeat, light-headedness and fainting episodes, occasionally leading to sudden death. Where drugs do not prove successful, the use of an implantable cardioverter defibrillator, a catheter ablation or a surgical ablation may be necessary. So treatments are available and the known symptoms can be detected through screening.

In instances of dilated cardiomyopathy, the main pumping chambers of the heart are dilated and contract poorly. This results in a low output of the blood from the heart. Occasionally, the right side of the heart is also involved, with fluid accumulating in the body tissues, particularly in the ankles and abdomen. Causes can include viral infection or an auto-immune disease. The immune system can be triggered to attack itself, and antibodies against the heart are found in approximately 30 per cent. of dilated cardiomyopathy patients, and in a similar proportion of asymptomatic relatives. In terms of genetics, dilated cardiomyopathy is familial in at least 20 per cent. of cases.

These conditions are well known. The symptoms are shortness of breath, lack of energy, swollen ankles, chest pains and arrhythmias. The treatment after effective screening is there: water tablets and angiotension, which converts enzyme inhibitors to reduce the amount of work that the heart has to do; there are receptor blockers and contractile performance enhancers such as digoxin, and beta blockers to improve the cardiac filling and reduce the work load on the heart.

I am not a medic, and I have taken the information from medical reports. I have been briefed by experts in the field, who have outlined the relationship between symptoms, screening and treatment. I hope that I am persuading the Minister.

Another group of problems are the ion channelopathies. They are genetic mutations that produce proteins that are found mainly on the outside of cells and regulate electrical activity. They are undetected in a post mortem, so it is crucial to understand what the symptoms are so that we can put in place a series of operational opportunities to diagnose.

Long QT syndrome is an ion channelopathy. It is the consequence of an irregular electrical pulse. Two of the potassium channels that regulate the behaviour of the potassium ions moving from the inside to the outside of cells are inefficient, or the sodium channel over-activates. This can be reflected in an ECG process as a lengthening of the period known as the QT interval—hence the name. There are no physical signs of the condition, which is why screening is so important. Diagnosis depends on observation of the ECG and may require repeated ECGs, exercise tests and a 24 to 48-hour tape monitoring. The symptoms are known: black-outs are the commonest, and there are palpitations and sudden death related to exercise or when startled, aroused suddenly or, sadly, when asleep.

The management of the disease is possible with beta blockers, pacemakers, cardiac defibrillators and lifestyle changes, which means avoiding strenuous exercise. There are many diseases, and I could go on in great detail. They include Brugada syndrome; Wolfe-Parkinson-White syndrome—which produces a very rapid heart rate but is usually completely silent and can be detected only with routine ECG screening; Lev-Lenègre syndrome, which is very rare, but well documented; and Marfan syndrome, an inherited disorder of connective tissue suffered by more than 5,000 people in Britain. The treatment suggested is regular ultrasonic scans to check the condition of the aorta wall and prevent a tear or ruptures. That can be done with beta blockers, or an operation may be required to strengthen the wall.

These conditions are well documented and presented academically in medical journals. The symptoms can be detected through screening, and there are clear and unequivocal corrective measures, including drugs such as beta blockers. The common factor in all the conditions is that screening can be seen to define diagnosis and support prescribed treatments. Nobody is under any illusion about the fact that some of these conditions will result in death, but surely not in the numbers that we have today—the best guess is four or eight a week. The conditions are inherited.

I have a little further to go. I promise the House that I will not be much longer—probably 15 minutes. *[Laughter.]* I wanted to give hon. Members a realistic hope and cheer them up.

What does the Bill suggest? Its aim is to achieve access to a screening process to confirm or identify a disease.

Mr. David Stewart: You mentioned screening. Were you disappointed that the National Screening Committee did not recommend a national high-risk screening programme, and do you take some hope—

Mr. Deputy Speaker (Sir Michael Lord): Order. I remind the hon. Gentleman that he must use the correct parliamentary language.

Mr. Stewart: Does my hon. Friend agree that it is important that the committee consider the issue again and introduce high-risk screening?

Ms Taylor: An excellent point. The committee is in fact not too unsympathetic to much that is suggested in the Bill. Although the use of language is loose and open-ended, it recommends a screening process, while I am keener to say that that should be tightened up and controlled. That will be my next port of call in lobbying.

The Bill is aimed at the recognition of certain symptoms, including palpitations, black-outs and breathlessness disproportionate to activity, that suggest the presence of a disease requiring screening to confirm or otherwise. It requests an acceptance that a "relevant cardiac specialist" is required to supervise the screening process, implying an acceptance that a specific and detailed research-based knowledge exists, so that an accurate diagnosis is possible. It requests an acceptance that a "relevant pathologist" is required when a sudden death has occurred, and thus an acceptance that in the case of inherited diseases such as hypertrophic cardiomyopathy, we need to know not only that the myocardium has become enlarged but that families will be told the details that the pathologist has determined. That is equally the case with dilated cardiomyopathy and arrhythmogenic right ventricular cardiomyopathy.

When sudden death occurs without warning or diagnosis of illness or disease or an awareness that the cause of death was an inherited gene, it is crucial that we gain more understanding and can give advice to relatives. The Bill provides for an invitation to screen first-degree relatives, those who are genetically related to people diagnosed with an inherited disease. The research guidance says that children have a 50 per cent. chance of inheriting the disease from parents, so we need experts to determine whether it was present and communicate the facts to relatives.

Communication of the cause of death by the professional groups to first-degree relatives or next of kin should include a support mechanism, a statement of the cause, and a pro forma confirming that the disease causing death was genetically inherited. All first-degree relatives would then be invited to attend an immediate screening process, which means that we would be behaving proactively, in the hope of a high take-up, with the aim of preventing potential life-killing diseases and saving lives.

The Bill is minded to acknowledge the heavy work load of all medics and suggests that, at all defined points of communication, a pre-written letter explaining the cause of death be made available—requiring only a named identification of the person who has died and the signature of the medic. A pro forma should include the medic's name, the name of the person who died and a request for all first-degree relatives to attend an immediate screening. Crucially, I have referred to countries such as New Zealand, which offer that service, but I want to make it equally clear to the House that there can be no insistence. The decision whether to take up the offers made by the medics is a matter for individual family members.

Throughout the Bill, there is an implicit acknowledgement of the significant amount of research knowledge about the details of the diseases with a potential to kill, and on the vital links in the chain of diagnosis of condition, which can be used as a screening process. Use of the language "relevant specialist" explicitly draws attention to that point. Additionally, the aim of the Bill is not to seek a national screening process, but a screening programme that immediately kicks in at the time when concern is expressed about the symptoms or condition that someone is suffering from. As I have said, it applies to first-degree relatives when an inherited disease is confirmed in one of its members at a time when a pathologist establishes the cause of death as an inherited disease.

The Bill, as I said, implicitly acknowledges the research-based specialist knowledge that exists, in the belief that it should be easily and universally accessed by cardiac specialists and pathologists. That knowledge informs an understanding of the disease that can cause death. It significantly informs a medical process that defines screening as the potential means to save life. The system of communication is not perfect—families use different GPs and are geographically mobile—but the mode of communication and the structures outlined in the Bill are significantly better than the current ones.

The Bill could have placed a further responsibility on GPs to establish a "family history", similar to a family tree with the genetic conditions indicated. Such information, if available, would most certainly pinpoint accurately those individuals who are at risk of inheriting a disease that has the potential to cause death. Such a family tree could ensure that from a young age, appropriate lifestyle and drug support could be suggested and utilised to manage the disease, with significantly increased competence to prevent a fatality. The suggestion of a family tree is not included in the Bill, but its efficacy is without doubt, which I hope will be acknowledged and eventually accommodated by the NHS.

I have taken a long time to outline—

Dr. Kumar: Not really.

Ms Taylor: My hon. Friend is too kind. I am well aware that I have taken a long time to outline to the House a very complex set of conditions and to express a clear hope that screening can be used to define and support families with certain conditions. As I said, sudden death traumatises families. Many—certainly the majority—fail to come to terms with the loss of a young daughter, son, father, mother, brother or sister, especially when they believe that their symptoms were disregarded or undiagnosed and their conditions left medically untreated.

In the Cardiac Risk in the Young (Screening) Bill, I have attempted to outline and use the practical knowledge and research of a small number of highly qualified and respected cardiac specialists. That information has informed the content and structure of the Bill's clauses.

The work of the cardiac specialist, Dr. Sanjay Sharma, supported by the academic physiologist Dr. Greg Whyte, has centrally informed the content of this Bill. In their working lives at the University hospital, Lewisham and the English Institute of Sport, they have gathered information on symptoms that suggest the existence of conditions that have the potential to be fatal. Additionally and importantly to the Bill, they have produced research-based information that positively shows the value of screening by a relevant specialist to diagnose potentially fatal diseases as well as to prescribe a lifestyle or medical treatment that will control the condition and significantly reduce—in some cases eliminate—its potential to kill.

I am indebted to Dr. Sanjay Sharma. His advice has been indispensable, his medical knowledge central to achieving a Bill that, if adapted or accepted, could support the achievement of a universal national service for people who are at risk in order to diagnose a potentially killer disease. I hope that the Minister will acknowledge that that information has come from a specialist in this medical field.

My final word of thanks is to the charity Cardiac Risk in the Young. The support I have received from its chief executive, Alison Cox, has been persuasive, creative and very thoughtful, and the Bill would not have surfaced without her support. The members of that charity, mostly families who have suffered the loss of a loved one, have equally provided an abundance of support. I am very grateful to them all. They, along with my close friends the Morland and the Bowen families, have been the source of inspiration for the Bill. I will be eternally grateful to all.

I am grateful to the Minister for the time she and her officials have spent debating the issues and advising me about the content of the Bill. My only request to her as I end my speech is that she wholeheartedly supports the intention of this Bill and sees the veracity and efficacy of screening to define and explain conditions and symptoms in the hope that the definitions and diagnosis can establish treatments that will save lives.

10.57 am

Mr. Eric Pickles (Brentwood and Ongar) (Con): I am grateful for the opportunity to make a brief contribution to the debate on the Bill. It is a pleasure to follow the hon. Member for Stockton, South (Ms Taylor) and I hope that she will not mind my gentle teasing when I say that I was a little concerned that she might be about to enter parliamentary history by talking her own Bill out. However, she made a powerful and important speech, following an earlier equally powerful speech on Wednesday night at the CRY reception. She has gone in considerable detail into the various complexities of the problem, and the whole House is grateful to her.

I apologise to the hon. Lady, to the Minister and to my hon. Friend the Member for Westbury (Dr. Murrison) because, on account of a constituency engagement, I doubt whether I will be able to be in my place for the wind-up speeches. It is my intention, however, to stay for as long as I can.

I particularly welcome the commitment that the hon. Lady received from the Chairman of the Health Committee to hold hearings and an inquiry into the problem. If Select Committees are designed to achieve anything, it is to give the sort of precise forensic analysis and scrutiny that the hon. Lady displayed in her speech. I have the honour to be one of the sponsors of the Bill. I was going to say that two people persuaded me, but it was three because, as we have learned this morning, the hon. Lady can be very persuasive. It is an honour to lend my name to her important Bill. As my moment in the sun disappeared last Friday, it is appropriate for me to say that her Bill is the most important of the whole batch of private Members' Bills in this Session.

As I said, I wanted to speak in this debate because of two constituents, one whom I knew very well and one of whom I did not have the honour of meeting, although I have met his very brave mother and, this morning, his father. The first person about whom I wish to

speak was my friend, Alan Gunnell. He was a young, serious man who was involved in the local party when I was first selected for Brentwood and Ongar in the early 1980s. We had an instant rapport. He was the kind of person most of us know from our local parties—serious and interested in politics. However, there was another side to Alan that I will long remember: he was a gifted mimic and he had a wicked sense of humour. He was one of those people to whom politics came easily. He had a natural rapport with the community and he was eventually selected to stand for a seat on the local council, which he won with enormous aplomb, such was his reputation.

A few short days after his second election, Alan sadly died. He did not turn up to an association event on a Sunday, which was unusual. We wanted to talk to him about various issues, so some of us left jokey messages on his answering machine. We did not know that Alan had passed away the previous evening. We did not find out until the Monday morning.

Alan was an only child and his parents were devastated. The effect of Alan's loss among his circle of friends was a deep sense of grief that continues to this day. A room in the local community centre was named after him, and life goes on. Only a few months ago, I held a surgery in the Alan Gunnell room at Tipp's Cross. I asked one particular constituent if there was anything else I could help her with. She said, "Yes, who was Alan Gunnell?" At that point, I felt a deep sense of anger, not at the constituent, because—as hon. Members will know—that way lies the route to madness, but because Alan should have been there. He should have been with me at that surgery. He was a man of great promise who did enormous things. He would probably have ended up in this place, and his loss is a loss not only to his friends, but to the wider community.

The second constituent, whom I did not have the opportunity to meet, was a young man called Ashley Jolly. Ashley was just 16 years old when he died in May 1998. He was a physically fit young man—as the hon. Member for Stockton, South said, that is often a characteristic in these cases. He played football from the age of six, he was a distance runner and he did the London to Brighton bike ride with his father. Ironically, he was awarded a prize for never having any time off school for illness. The day he died, he had a happy, peaceful day tinkering with a go-cart with his father. He went to bed, but he did not get up.

Ashley's parents were told that he had almost certainly died from asthma, and that was the verdict of the post-mortem. However, his mother is a remarkable woman and she realised that the verdict was not right. She looked on the web and made inquiries. She began to understand what had happened and informed herself about the electrical workings of the heart. She started a website and others wrote to it. She discovered an organisation called the Sudden Arrhythmia Death Syndromes Foundation—or SADS—in the US, and there are similar organisations in Australia and Canada. She took the brave step of forming the UK branch of SADS and organised a seminar to discuss the issues with other charities concerned with the problem of cardiac arrest. Another conference will be held in June at the Oxford genetics knowledge park.

Ashley's mother was later joined by Penny Hurrell, whose daughter Louise I mentioned in an intervention in the hon. Lady's speech. Louise was 12 years old when she died. She had had Wolfe-Parkinson-White syndrome since she was a toddler, but the family had been told that there was nothing wrong. However, a simple treatment could have ensured that she lived a long and happy life.

A common myth exists that if one is diagnosed with a condition that causes sudden arrhythmic death, one has no alternative but to wait to die. As the hon. Lady clearly demonstrated, that is not the case. The treatment is often simple and does not mean an invasive operation, but a course of drugs.

We meet at a time when our nation's attention is focused on the tragic deaths in a terrible terrorist attack in Spain. We have met on many occasions after accidents on our railways or on the roads. As my constituent Anne Jolly said to me yesterday, "If all our children had died on the same day, there would be a public outcry. Because they happen in isolation, we often feel abandoned by the system." The Bill offers a chance to end that feeling.

The hon. Lady said that the conditions that she was talking about are rare, and that is right, but they are not uncommon. I was very struck by discussions with fellow MPs in the Tea Room and at the reception on Wednesday, because it was clear that most of us know of such cases. Most of us have not just a constituency connection, but a personal connection to the issue. The hon. Member for North Durham (Mr. Jones) asked the hon. Lady for information about what is happening in other countries, but the truth that we have to come to terms with—and it is not easy—is that if we were Italian, French, Canadian or Australian we would have a better chance of surviving such conditions than as British citizens. That is a result not of policy, but of a combination of ignorance and neglect. These illnesses have been a hidden killer that we have not entirely understood. Families have been robbed by these illnesses, and so has society, of bright young people who should have lived full and happy lives.

The hon. Member for Tynemouth (Mr. Campbell) asked, "What is young?" That set me thinking about the commonality in all these deaths: shock. Such deaths should not happen to a young healthy person, an athlete, someone who receives awards for never taking time off. Doctors simply do not believe that anything could be wrong when such a person goes to see them. The Bill offers us a chance to address that reverse ageism, to ensure that young people and families, like all of us, have the right to enjoy a long, happy and productive life.

11.10 am

Mr. David Stewart (Inverness, East, Nairn and Lochaber) (Lab): My hon. Friend the Member for Stockton, South (Ms Taylor) deserves the highest possible praise for using her elevated position in the ballot for private Members' Bills to introduce this excellent Bill, which I fully support and endorse. My hon. Friend made a first-class speech, which was articulate and informative.

May I apologise to the House, as I shall be unable to stay for the wind-ups? I have a family engagement.

Few events in life can be more traumatic for parents than the death of a child, or the death an adolescent son or daughter. I speak with some personal experience, as 10 years ago, I tragically lost my nine-month-old son Liam, through cot death.

Over the years, I have met and worked with scores of bereaved parents. Support, understanding and counselling can, of course, help parents and children to come to terms with bereavement, but no one can answer the big question, "Why me?"

Ms Dari Taylor: My hon. Friend carefully and accurately says that the loss of a child would traumatise any family, but may I kindly ask him to extend that comment to include young husbands, young wives and young brothers and sisters, whose families are equally affected in such situations?

Mr. Stewart: My hon. Friend makes a very valid point; we sometimes forget the wider family network, which is incorporated in the Bill.

The effects on parents of the victims of sudden cardiac death are no different whatever the age, and, as we heard earlier, it is the main cause of death in those aged under 35. We also heard that the condition kills between four and eight young people in the UK each week. The *Medical Journal of Australia* reports that one in 200,000 school or college athletes will die suddenly, most without prior symptoms.

There is much concern about risk factors. On 18 February 2002, the *Medical Journal of Australia* identified a few of the factors to which my hon. Friend referred earlier; they included family history, previous cardiac arrest and links to genetic mutations. In July 2003, the journal *Heart* reported survey evidence showing that 80 per cent. of sudden cardiac deaths in athletes occurred following, or during, vigorous exercise.

May I refer to an example that my hon. Friend touched on earlier? In 2001, in the constituency of my hon. Friend the Member for Western Isles (Mr. MacDonald), a 24-year-old school teacher, Joanna Fotheringham, died suddenly in her sleep. The charity Cardiac Risk in the Young—about which we have heard so much today and which I fully support and congratulate on its work—led an excellent initiative with the Western Isles council and the Western Isles health board. They conducted ECG tests on 600 young people aged between 15 and 18. That was the first time in the UK that such a programme had been undertaken routinely for heart disease. The charity rightly wants British health authorities to back nationwide cardiac screening—albeit in a highly targeted way—such as that in Italy and America.

Alison Cox, the founder and chief executive of CRY said of the Western Isles scheme:

> "Our programme in the Western Isles aroused considerable media interest . . . with moving interviews with Alex Fotheringham"—

the father of the young teacher—

> "talking about the devastating impact on her family of Joanna's sudden death, and George Moodie, Joanna's headmaster on Lewis, explaining how the sudden cardiac death of a young and much loved teacher like Joanna affects the whole community".

I should like to touch on another semi-local issue. A few weeks ago, my local newspaper, the *Highland News,* launched a campaign to raise £3 million for a dedicated, cardiac rehabilitation and research unit. I congratulate the newspaper, as that project is very much in the spirit of my hon. Friend's Bill.

Screening is vital. As we all know, national screening programmes are usually carried out following advice from the UK National Screening Committee. In 1996, the previous Conservative Government said that no new programmes could take place until the committee had analysed their effectiveness. Although the NSC rejected screening for sudden cardiac death in the young, the evidence base is being reviewed this month and I am sure that the whole House looks forward to a more positive response from the committee.

Why do I support the Bill? I believe that high-risk, targeted screening, not general population screening, is vitally important. I believe that an automatic right to screening for all relatives of people who have died from sudden cardiac arrest is crucial. Relatives will have a high motivation to participate, so such screening will be highly effective and efficient. As the causes of sudden death in young people have a genetic link, family screening is imperative.

This is a first-class, well researched Bill. My hon. Friend deserves congratulations on her initiative in introducing it, and I strongly commend it to the House.

11.16 am

Mr. Nigel Jones (Cheltenham) (LD): It is a great pleasure to support this important Bill, and I congratulate the hon. Member for Stockton, South (Ms Taylor) on introducing it, and on the huge detail that she gave us about the various conditions and treatments for which she wants screening to be available. I also congratulate her on the passion that she showed in her speech.

I am a sponsor of the Bill, and I suspect that the main reason why the hon. Lady invited me to be a sponsor is that I am one of the few Members to have had a heart attack. I do not recommend the experience, and I would like to help colleagues to avoid it if possible, so I thought it might be useful to the House in considering the Bill if I explained some of my first-hand experience of the conditions that the hon. Lady was talking about.

First of all, finding out that one has a heart problem is a gigantic shock, not just for the patient but for their family and friends, too. On 7 November 2002, I was suffering from what I thought was just a heavy cold. I had just returned home from one of those weeks in this place when there had been a lot of votes and, in the Lobby, everyone was passing on germs from all over the country.

After hours of coughing and spluttering, I started to have real problems breathing. I eventually told my family, "Call an ambulance, I think I might be dying". Gloucestershire ambulance service arrived very quickly to give me oxygen and the paramedics walked me out to the ambulance. I want to put on record my enormous thanks to the paramedics for their promptness and professionalism.

In Cheltenham general hospital I lost consciousness for a time. A little later, my wife was taken into a corridor and told to prepare herself for the worst. My heart was not pumping properly, and my lungs were full of fluid. The doctors thought that they were going to lose me. I cannot find words of praise sufficient to thank the people who treated me. However, suffice it to say that they managed, eventually, to drain the fluid off my lungs and to stabilize me. An hour later my wife, son and daughters were allowed in to see me and the look of relief on their faces will live with me for ever.

The following day, the cardiologist, Dr. Challoner, whom I have tasked with keeping me alive, told me that I had suffered a heart attack. What he actually said was that I had had a myocardial infarction, or MI, which is what doctors like to call heart attacks. I had suffered no pain, so in that respect I was lucky, but the evidence from the blood tests was clear—it was a heart attack.

The doctor had been keeping an eye on me since 2001, when it was discovered that my heart had an irregular beat—a condition called atrial fibrillation. I underwent an electrical cardioversion, which the hon. Lady mentioned, when under general anaesthetic paddles were used to stop and restart my heart to try to restore a normal heartbeat. When I woke up, I asked the anaesthetist whether the procedure had been successful. "No," she said, "we had six goes, but they didn't work." She added, "And you snore." That was a year and a half before the heart attack, but a week after my heart attack, I underwent an angiogram, which the hon. Lady described. It is a process where a tube is inserted into the groin and fed along an artery into the heart and, using a dye, it is possible to see the function of the heart and detect any problem. Normally, an angiogram is a 20-minutes procedure, carried out under local anaesthetic—not in my case.

During the angiogram, the doctor was surprised to discover that my heart attack had caused only a tiny amount of damage in a single vessel of a side artery. He said that he could not understand why I had been so ill, with just a tiny bit of damage. I was able to watch what was happening on monitors in the room. It was fascinating—but frankly, it would have been even more fascinating if it had not been my own heart that I was looking at. The 20 minutes passed. My cardiologist left the operating theatre. A nurse kept giving me a spray under my tongue to stop the pain. I told her that I had no pain. She seemed surprised. A second cardiologist arrived. After a certain amount of prodding, he told me that they were thinking of transferring me to Oxford, where they have better facilities. He pointed out that there were advantages, including an opportunity for travel. At that stage, I wondered whether I ought to consider a spot of praying. Anyway, after a total of two and a half hours, what I had expected to be a 20-minute procedure was over.

Ms Dari Taylor: I am finding the way in which the hon. Gentleman is presenting his argument very engaging, but I want to ask a specific question. At that stage, he was invited to go to Oxford—probably to the Radcliffe hospital—and not asked to remain in his local NHS hospital. Is he suggesting—I would most definitely think this relevant if he were—that the some people's expertise is greater than others and that it is time that that was more acknowledged and more utilised in the NHS?

Mr. Jones: That is a really good point. There are certain centres of expertise, and, yes, we should make more use of them. In fact, I should like to see more centres of expertise in local communities. People in my constituency either have to go to Oxford or Bristol if they have a serious condition. What happened in my case was that, during the angiogram, I suffered another heart attack on the operating table. There was no pain. I did not know about it, and the doctors and nurses did not tell me. Frankly, I might have panicked if they had.

Ms Taylor: Does the hon. Gentleman agree that certain cardiac specialists have greater knowledge than others and that that should be clearly understood in the NHS?

Mr. Jones: Yes, and not only the knowledge, but the equipment varies. There is far more equipment at the Radcliffe hospital in Oxford and, indeed, at the Bristol royal infirmary, where I went later, than in Cheltenham. I should like to see more equipment in the local community, which is something that we can campaign for.

Where was I? I had just had my second heart attack. I had tubes in me, and the cardiologist told my wife, "We're having terrible trouble with him. He won't behave at all." To which she replied, "Nothing new there, then." The angiogram had turned into an emergency procedure—an angioplasty, where a balloon is inserted into the artery and inflated, and a piece of titanium mesh, called a stent, is inserted into the artery to keep it open. Astonishing though it may sound, the heart does not seem to object to titanium. In fact, I am told that, once it is in place, new cells grow on the inside of the stent. I was only the second person to have an angioplasty at Cheltenham general hospital, but it has since become a routine operation, so perhaps some good came of my experience.

It appears that one of my arteries had a problem that my cardiologist believes is a genetic fault, which is relevant to the Bill. It was something that I had inherited from my father, who died from a heart attack in 1985. It is possible that my children may also carry that genetic fault. In other words, there is a family history of cardiac problems. That is why the Bill is so important. We have already heard heart-rending stories about young people who have died suddenly. We all share the grief of their families. We were all struck particularly by the death of Marc-Vivien Foe, the talented Cameroon footballer. I know what it is like to lose someone close to me. Colleagues will know that, four years ago, I lost a close friend, Andrew Pennington, during an attack in my constituency office. That was a ghastly experience, both physically and emotionally, and the scars remain, but to lose a son or daughter, sister or brother, mother or father, wife or husband must be so much worse. I do not want to think about the anguish that I would feel if any of my children were to die before me, particularly knowing, as I do, that there is a family history of cardiac problems.

I could go on to tell the House about the further incidence of breathlessness that I suffered last April. There seems to be some appetite for me to do so. It was not a heart attack this time, but something called flash oedema, which presents similar symptoms. Again, an ambulance was called and arrived swiftly. Again, I walked to the vehicle and was taken to the hospital. Again, I lost consciousness, and my poor wife was told, by the same person as before, to prepare herself for the worst. I was unconscious for 12 hours, and I woke up

with a horrible tube down my throat and a machine breathing for me. It was one of the most unpleasant experiences that I have ever had.

I was kept in hospital for two weeks, including being transferred to the BRI in Bristol, where I underwent a number of further tests. Those tests included another angiogram, which discovered that my stent is working well; several ECGs, which the hon. Lady has discussed; an echocardiogram; and, worst of all, a 40-minute MRI scan, where the patient lies in a tunnel and pictures are taken. In my case, the pictures were of my heart and kidneys. I do not normally get claustrophobic, but an MRI scan is just awful.

Ms Taylor: The hon. Gentleman is very generous in giving way; but, again, I need to ask this question, and I am looking forward to hearing the answer. He is explaining in some detail the care and responses of medics to his conditions, and we are all impressed. We are all delighted—it is such a pleasure to see him looking so well on the Floor of the House today—but does he accept that, if he were 22 and not over 40, the responses to his conditions might have been significantly less?

Mr. Jones: The hon. Lady is very generous to say that I am over 40—it is a bit more than that, actually—but she is right about inverted ageism, which might have affected me if I had been 22, rather than 50-something, at the time.

After all those tests, no reason could be found for the event last April, which is a bit worrying. It was definitely cardiac-related, but my cardiologist was unable to say what caused it or that it would not happen again. If I suddenly sit down, it may be happening again. He suggested that it might be "an occasional electrical fault", which made me sound like an old Vauxhall a friend of mine once owned. Regular checks are continuing, including daily blood pressure tests, which I carry out myself. I am currently taking five types of medication, some of which the hon. Lady mentioned. They including a medicine to control the atrial fibrillation; a mild diuretic to stop a build-up of fluid; a statin to control cholesterol; a calcium channel blocker—its role has been explained to me many times, but I still do not quite understand what it does—and an anti-coagulate to thin the blood. It is likely that I will have to take those tablets for the rest of my life.

I asked my doctor how ill I was on a scale of one to 10, where 10 was falling over completely. He told me that when I came in to the surgery, I scored nine and a half, but that I was now probably about two. One doctor who took my blood pressure said, "Oh, you've got blood pressure to die for", which I thought was an inappropriate description in the circumstances. Another doctor explained that the recovery time for a broken limb is six months, and that it is six months for a heart attack too. I had two heart attacks, and it took me a year to recover. Colleagues may have noticed, although it is more likely that they were too busy with their own work, that I was not around Westminster much during that year of recovery. Of course, I came here for the key debates and votes, especially on Iraq, but during my recovery, I followed to the letter the advice that I was given by my cardiologist and those in the splendid cardiac rehabilitation team in Cheltenham, who told me that if I continued working the same number of hours, I was going to kill myself. They are not too impressed by the lifestyle that Members of Parliament endure.

I must say that my colleagues, including my party leader and Chief Whip, were wonderfully understanding and supportive. That is unusual for a Chief Whip. My staff worked tremendously well, making sure that we dealt with all the constituency case work. I also received numerous "get well" wishes from my constituents, and it all helped with the recovery. I simply do not know how much my treatment has cost the NHS. It certainly cost many thousands of pounds. The titanium stent alone cost £5,000—my wife says that it more than doubles my value—and there was also the time that the wonderful NHS staff put in, including ambulance paramedics, the doctors and nurses who resuscitated me twice and looked after me in hospital, and two cardiologists; we had only two cardiologists in Cheltenham, and at one stage, they were both working on me at the same time. They spent a considerable amount of time with me. Those involved also included the technical staff who analysed all the tests and the anaesthetist who told me that I snored. I spent a total of four weeks in hospital. The process must have cost thousands and thousands of pounds.

The point that I want to make to the Minister—perhaps she could pass it on to the Treasury—is that screening those at risk, who we know are at risk because it is likely that they have a genetically inherited condition, can avoid much of the expenditure involved in the treatments. Accepting the Bill would not only prevent a person from dying but help the Treasury, as that person would become economically active and might remain so for decades. That would benefit not only the person concerned, in living a full life, but the economy and the Treasury.

I believe that it is in the Government's economic interests to pass the Bill into law, and I hope that we will see its modest proposals accepted. It is sensible and the proposed measures should be best practice. It will prevent many tragedies and much emotional turmoil. It will save not only precious lives, but scarce resources, and the Government will win a lot of credit and gain a lot of friends by grasping this opportunity.

11.34 am

Ms Meg Munn (Sheffield, Heeley) (Lab/Co-op): My constituent, Jason Howell, is a lucky man. He is married to Michelle, known as Shelley, and he is the father of two children, Georgia aged nine and Tom aged seven. However, it is not the joys of family life that make him lucky. He is lucky because he is alive. Unlike many of the people whom we have heard about today and those who suffer unknowingly from the conditions that have been mentioned, Jason Howell has cardiomyopathy, but was diagnosed as having it. Now in his mid-30s, like many of the people whom we have heard about today, Jason had always played football several times a week. He worked, he never smoked and he had only the odd drink.

Six years ago, Jason had a cold. Somehow or other, he felt that there was something wrong; his situation was like that of the hon. Member for Cheltenham (Mr. Jones). He went along to his doctor's surgery, but his usual general practitioner was not there and he saw a locum. Thankfully, that doctor—from what I have heard today, this is unusual—took my constituent's concerns seriously. She told him that he needed a thorough examination, to which he agreed. To his surprise, within 24 hours, he found himself in hospital. This is a young man who must not yet have been 30 and found himself diagnosed with a heart condition—a condition that he tells me has caused his heart muscle to thicken, making it difficult to pump blood around the body efficiently.

Following that diagnosis, Jason was off work for some four or five months. During that time, he did not feel particularly lucky; he felt like saying, "Why me? Why has this happened to me and my family?" There was very little information around, and he did not know what the condition meant for him. As we have heard time and again in the debate, our health services are used to dealing with people with heart conditions who are somewhat older. There is advice around and there are support groups. Such people are told how to manage their condition and what to do. Jason Howell, who was not yet 30, did not quite know what the condition would mean for him and his family, and for the rest of his life. He did not know whether it was okay to exercise. We know that when people have heart attacks, they are often told that exercise is a good thing after a period, but he did not know about that. One doctor said that it would be okay, but his doctor said that he should not really do any strenuous exercise, as it was a problem.

Jason had worked for Black and Decker for a long time. He was a machine setter, and he had worked his way up to be a manager. The company experienced some problems, so he decided that, rather than wait to be made redundant, he would seek employment elsewhere. He got a job with a food manufacturer. Throughout this time, he generally felt well, but he had had the occasional dizzy spells, which, as we have heard, are a symptom of some heart conditions. However, he was having regular scans with nothing to worry about, and he was told that he could carry on his life as normal.

Working in a food factory meant that one day, Jason went into a fridge freezer at minus 16° C. That is the last thing that he remembers. He was later told by his work colleagues that he was missing for about an hour before somebody realised that he was missing, and he ended up in Rotherham hospital. Nobody told him that such conditions might be a problem, but he learned that extreme cold and heat were dangerous to him and could exacerbate his condition. I am not a medical expert—like my hon. Friend the Member for Stockton, South (Ms Taylor), I rely on what other people have told me—but I am aware that the temperature meant that the difficulty that Jason already had in pumping blood around his body was exacerbated.

At that point, Jason decided that it was no longer sensible for him to carry on working. He is now at home most of the time, and he experiences occasional blackouts and dizzy spells, but carries on as best he can in looking after his children and experiencing the joys of family life, which have perhaps become more precious to him than to most of us. He has had a pacemaker fitted to help in trying to find out more about what the dizzy spells and blackouts mean. As my hon. Friend said, there are ways of treating these conditions and finding out more about them. Jason explained to me that, when he experiences dizzy spells, he can switch on the pacemaker so that it records what is happening in his heart, after which the readings can be downloaded, so that the experts have some understanding of what has been happening to him.

Jason is not just worried about himself, because he has learned that first-degree relatives are likely to be at risk. As the hon. Member for Cheltenham explained, the sufferer's children may be affected, although at this stage, thankfully, there does not appear to be a problem. Jason's children have to be scanned regularly. Like many children, they are keen on sport. Nine-year-old Georgia is a keen runner involved in a local athletics club. Jason's seven-year-old son Tom supports Sheffield United—thankfully, he is not a Sheffield Wednesday supporter—and is a keen footballer. However, the condition may affect them, and their health has to be checked regularly. Jason's brother, incidentally, was a triathlete.

While Jason feels incredibly lucky to be here, he and his family feel isolated. Tragically, most people die before they are diagnosed, and Jason does not know anyone who is living with such a condition, so there is no one with whom he can share his experience. Many families who suffer traumatic events or people who are diagnosed with particular conditions turn to self-help groups or national bodies. Cardiac Risk in the Young—CRY—has provided Jason with help and information, but he does not know anyone else who is living with the problem. He has been told that 98 per cent. of people with the condition die before they are diagnosed. He is lucky to be here and fortunate that the locum GP had the skills to recognise the problem. However, although he has the support of his friends, family and CRY, he feels isolated. Who can he talk to about his experiences and situation? He is 35 and looking ahead, but there is no one else in his position, which is difficult and isolating for him.

CRY has been enormously important to Jason and his family in providing information so that they can understand his condition more. When someone is first diagnosed with a condition or something happens to a family member people want to know what services and support are available, how they can manage the condition, what their family should do and what is the best way forward. Organisations such as CRY help families to live as normal a life as possible.

Ms Dari Taylor: Once again, I am listening with great attention. Does my hon. Friend dispute the statement regularly made by people, including some medics, that families and young people do not want to know about those problems and resist screening? Does she agree that there is no evidence to support that statement?

Ms Munn: I completely agree with my hon. Friend. One has only to visit a family such as Jason's to see how important it is that people know about their condition. Having the opportunity to find out whether something is wrong and being able to manage it makes a huge difference. I do not know a great deal about my constituent's medical details, but if he had had the opportunity to be screened and had discovered his condition earlier, he might have done less damage to his heart. It is difficult to answer such questions retrospectively, but the use of screening to identify such conditions at an early stage is important.

I therefore congratulate my hon. Friend, who is also a good friend of mine, on choosing to tackle the issue in her Bill, which raises awareness and seeks to save lives. Those of us who have the honour of sponsoring it have learned more about certain heart conditions today and, because of the way she set out her aims and because of the case studies provided by CRY, we realise that it is even more important than we originally thought. Ultimately, it gives families who have suffered terrible losses or who, in a few cases, are living with such conditions hope that something can be done to prevent young people from dying suddenly.

The Bill also provides hope for the children and relatives of families who have suffered. We live in an age in which we generally expect to have a long life and do not expect children and young people to die, so we forget that many people have suffered the deaths of young children and relatives. We do not share such experiences enough and, as has been said, we do not bring the statistics together, so we think that they are isolated cases. Anyone who has lost a close friend, a child, a brother or a sister has experienced a tragic loss and knows that lives can be derailed. People become less able to work for a period, and may suffer from depression. The impact of

someone's death on family and close friends can be huge, and we often deny that in our busy lives. We must get to grips with the problem by offering screening services, providing information and improving knowledge among clinicians at all levels, so that they know that the young person who has walked into their surgery with a seemingly innocuous problem may in fact, as in Jason Howell's case, have a life-threatening condition.

Counselling and support are important, and can sometimes be provided by close family and friends, but it is helpful at other times to provide professional services. People such as Jason Howell and his family do not just need information know about how they should live their daily lives, but a way of coming to terms with change. Jason is a young man who, like many of his friends, has a young family. Before his diagnosis, he expected to play football regularly, go to work and play with his kids, but he suddenly discovered that his life was restricted. How did he and his wife deal with that? How did they rearrange their lives, and how did their kids feel? How did they understand that daddy cannot do what he did before and how do they live with the possibility that he may have a shortened lifespan? Let us hope that that is not the case, but how do they come to terms with the problem? Support is therefore essential in helping people to continue functioning and live their daily lives.

It is good to know that it is not just in this House that elected representatives are campaigning on the issue. My local Member of the European Parliament, Linda McAvan, has campaigned with other MEPs. She first became aware of the problem when someone who worked for her son died from the condition at the tragic age of two. Last year, the World Health Organisation agreed to investigate these sudden deaths to try to gain some understanding of the wider situation, not just in the UK. Over 100 MEPs have signed a petition campaigning for a specific code to be added by coroners in such cases so that they can collate information about sudden death in young people, possibly from a number of different conditions, as my hon. Friend the Member for Stockton, South so ably outlined. Collecting and checking the information may lead to a better understanding of the problem.

The various conditions are difficult to diagnose. The Cardiac Risk in the Young booklet states that, in many cases, there are no symptoms. How can anybody be expected to diagnose such a condition? However, there are cases in which symptoms begin to show themselves, so collating that information, having some means of looking back over it, and establishing whether the outcome was, say, four deaths a week or eight deaths a week would help us to advance our understanding of the conditions.

In summary, the life of my constituent, Jason Howell, is not what he thought that it would be—a young dad who worked, played football and played with his kids. Instead, he is living with a life-threatening condition, but believes he is a lucky man to be still alive. He wants more people to be given that chance. To do that, we must find out what can be done through screening, raising awareness of the conditions and providing information to families who have suffered terrible deaths or who are living with those conditions.

11.52 am

Dr. Julian Lewis (New Forest, East) (Con): Sometimes there are visual images that stick in the mind from a film, a television programme, a documentary programme or a memorial programme. One of those occurred some years ago, around the time of Armistice day. I think that it was a film by Ken Russell. Towards the end, the camera zoomed in on one of the thousands of graves in an allied cemetery in Flanders. There was some music playing, and gradually the camera began to pan along the tombstones. The music speeded up, and the camera went on and speeded up. By the end of the programme, the camera was moving along a line of tombstones with no end in sight. One was left with the impression of a terrible roll call of bereaved families who had lost young people, in large part unnecessarily.

I was reminded of that image while listening to the hon. Member for Stockton, South (Ms Taylor) when she introduced her Bill. She should make no apology to the House for having taken some time to do so, because she was giving the equivalent of that camera image: she gave a roll-call of young lives that had been snuffed out, in many cases unnecessarily. I am proud to be a sponsor of her Bill, which endeavours to save as many young lives as medical science possibly can from such a cruel fate.

As well as paying tribute to the hon. Lady, I pay tribute to the hon. Member for North Durham (Mr. Jones), whose contribution I look forward to hearing if he is fortunate enough to catch Mr. Deputy Speaker's eye. He took up the mantle of forming the all-party parliamentary group on cardiac risk in the young, of which I have the privilege of being vice-chairman, while he has the burden of doing the work. I think that he would agree that it is significant that every speaker so far has come to the House motivated not by some general analytical interest in, or specialist knowledge of, the subject, but invariably by some personal experience of it.

In my case, as I explained on 21 June 2001 when I had an Adjournment debate on cardiac risk in the young, it was because a young constituent of mine, Adrian Woodhead, had come to my surgery and told me of the loss of his wife, Sarah, at the age of only 28. She was a young lady who had everything in front of her and who had the typical profile of not having any history of ill health, being immensely fit and strongly athletic. She died suddenly and without warning.

I said to the House then what Adrian said to me, and I repeat it now, with the indulgence of the House. He said:

> '"I expected the house to be full of noise and life, as you get from children, not silent through death and loneliness . . . There is no structure to my life except for my work and my efforts to ensure that someone else might not have to go through this . . . I can do things for other people, but I can do nothing for myself."'—[*Official Report*, 21 June 2001; Vol. 370, c. 273.]

One of the things that he did for other people was to interest and involve his local Member of Parliament in that cause.

One of the things that was explained to me by Alison Cox, who has justifiably been singled out for immense praise in the debate for her pioneering work in founding Cardiac Risk in the Young, was that the reason why it was difficult to create a groundswell of opinion about the problem was that, first, it was unexpected when sudden death syndrome struck; secondly, there were few survivors of it; and thirdly, therefore, anybody who might do anything about it would probably come from a family who had experienced a shocking bereavement. What a tribute it is to those families that so many of them have turned shocking loss into positive action. Once those

groups sprang up, we found no end of examples of tragedy striking in that way, and because people were beginning to articulate it and organise around it, tremendous progress has been made. In response to the debate in June 2001, the Government pledged substantial funds to Cardiac Risk in the Young, which it received and put to good use in its pilot programmes for screening.

Although the work that has been done and the awareness that has been raised are admirable, the Bill is an essential further step, because we have to ensure that where tragedy strikes, it is not then unnecessarily multiplied. A key provision of the Bill is to make certain that the families of those who have been afflicted by sudden death syndrome are automatically screened. There is no excuse for not doing that when lightning has already struck.

Earlier, we heard a question about what happens in other countries. It is worth sharing with the House the background to how Alison Cox came to be involved in her campaign. She was aware that, back in the 1970s, a well-known rising tennis star called Karen Krantzke had died as a young woman. About 20 years later, Alison's son Steven was on the verge of a promising sports career and had won a sports scholarship to a university in America. Because of previous litigation, that college had established a screening programme. For that reason alone, it was discovered that Steven Cox—whose father was the famous tennis player, Mark Cox—had one of these conditions. That discovery almost certainly saved Steven's life, as I am sure that he would acknowledge if he could hear me—which, although I am not supposed to mention it, I believe he can. Alison was inspired to do something about the situation because she saw how little progress had been made in the period between the death of young Karen Krantzke and the narrow escape of young Steven Cox. I salute her for what she has done.

As for comparing this country with others, I can throw a little light on that by citing the example of Germany. At the time of my Adjournment debate in June 2001, there were only 17 implants per million citizens in this country, but more than 60 per million in Germany and more than 200 per million in America.

Does screening help? One of the matters that caused me some concern at the time of the debate was a ministerial letter replying to Earl Howe on 8 May 2001, which, although designed to be helpful, stated that

> "screening does not identify all those affected"—

by sudden death syndrome—and that

> "there is little evidence at present that treatment before the onset of symptoms alters the course of the disease."

The hon. Member for Stockton, South rightly shakes her head. No Minister would make a statement like that today. Significant numbers of people have an opportunity to survive the condition provided that it is identified in time.

There remains the ethical question of whether parents of children who are at risk of sudden death syndrome want to know whether their children are susceptible or would rather not know, given that, in some cases, the onset of the attack will nevertheless be unavoidable. Alison Cox told me that, of the hundreds of people affected by cardiac risk with whom she had dealt, only one mother said that she wished that she had not known that her child was vulnerable. Far more typical of people's reactions was that of my constituent, Adrian Woodhead, who said:

> "It doesn't matter what condition you have—you just deal with it. But to deal with it, you've got to know."

That is by far the most widespread view.

I conclude on a happy note. Several references have been made to the reception two nights ago on the House of Commons Terrace that I sponsored together with the hon. Members for North Durham and for Eastleigh (Mr. Chidgey). Towards the end, I was delighted to find that my constituent, Adrian Woodhead, was present, and he approached me. He had rebuilt his life and was accompanied by his charming girlfriend, Jenny, who proudly wore a badge that stated, "CRY supporter". We are here debating this important Bill only because of the spirit of people such as Adrian Woodhead and the other fine families to whom so many hon. Members have referred.

I congratulate the hon. Member for Stockton, South on promoting the Bill and Alison Cox on founding CRY. Above all, I congratulate the relatives and the survivors, to whom we all owe so much.

12.06 pm

Mr. Kevan Jones (North Durham) (Lab): I support this important Bill and congratulate my hon. Friend the Member for Stockton, South (Ms Taylor) on promoting it. The hon. Member for Brentwood and Ongar (Mr. Pickles), who unfortunately cannot be in his place, made a moving speech. He summed up the matter well when he described the sense of loss of his friend, Alan. As the hon. Member for New Forest, East (Dr. Lewis) said, many hon. Members come to the subject through experience of personal tragedy.

I congratulate the hon. Member for Cheltenham (Mr. Jones) on his graphic and sometimes amusing description of his difficulty with heart disease. He gave an insight into the benefits of the health service and the debt that he and many others owe to hard-working health service staff.

My hon. Friend the Member for Stockton, South highlighted not only a condition that leads to sudden death in young people, but the fact that each death is a

personal tragedy for the affected family. It is always difficult for a family to deal with sudden death that takes a loved one. It is even more difficult to come to terms with the death of a young person. As other hon. Members have said, the anguish and sense of loss is compounded when medical authorities cannot explain why a fit, healthy young person suddenly dies. That adds to the emptiness, and to the questions that the family has to ask. We all want logical answers to the question of why things like sudden death happen. Often, families are simply left to ask why and to question what could have been done to turn the clock back. The Bill makes a practical suggestion for helping to prevent such tragedies from occurring in other families.

I, too, came to the subject through a personal tragedy, which friends, Jeff and Sandra Morland, suffered. They are also good friends of my hon. Friend the Member for Stockton, South. Their 22-year-old son died just after I was elected as a Member of Parliament. Jeff, a full-time trade union official, is a good friend of mine from the trade union movement in the north-east. He is a proud father of three and head of a close and warm family. Levon was a twin and a young man who had everything to live for. He was an outgoing, bubbly and popular character with a sense of humour. In the past few years, the family have had to deal with tragedy and sense of loss. It has been heartbreaking to watch.

Levon suffered from shortness of breath for the first time when he was 12 years old. One minute, he was feeling fine; the next minute, he was breathless, as though he had been running. The first time this happened it lasted only a few minutes. Over time, however, it took him longer and longer to recover his breath. After a few months, his parents took him to see his doctor. He had a series of tests and was diagnosed as having Wolfe-Parkinson-White syndrome. Levon's twin brother, Aran, was also tested but found to be clear. The fact that they were identical twins makes it even more difficult for Levon's family and friends to deal with his death.

I have here a letter written by Aran shortly after Levon's death. It begins:

> "To My Big Brother, a letter from the heart."

With the indulgence of the House, I would like to refer to parts of it. Aran describes very movingly how Levon came to terms with his diagnosis, and how he referred to it as "a nuisance" and said that it was nothing to worry about. That summed up Levon's attitude to his illness. He suffered an attack every couple of months, but as soon as the attack was over, his mind would turn to other things. He was determined to live life to the full. He had regular check-ups with his doctor, and the family was told that his symptoms were not getting any worse.

Aran describes how, at the age of 18, Levon went to be a travel rep in Magaluf. He describes his brother as being full of fun and the

> "life and soul of the party".

Aran describes how he and his girlfriend, Kim, went on a visit to see Levon working in Magaluf, and tells how everyone thought that he was a healthy, outgoing and popular young man. Levon had regular check-ups, and it was explained to him that he could have an operation. It was also pointed out to him, however, that there was a 10 per cent. chance that he would not survive the operation. Aran explains in his letter that Levon's approach to this was to say,

> "What's the point? It's not worth the risk."

He felt that he could live with the condition.

Levon's thirst for life led him to go travelling in north America. Unfortunately, he suffered another, more serious attack when he was in Mexico. This time, it lasted for three hours. On his return to the UK, however, his desire for life and his bubbliness and strength of character were undiminished. One of the last things he told his brother was that his ambition was to appear as a contestant on the popular TV show, "Big Brother". Sadly, he did not realise that ambition.

The final part of Aran's very moving letter describes the dreadful circumstances in which he found his twin brother dead in bed, still wrapped in his bedclothes. He had tragically died while suffering an attack in his sleep, his heart finally having given out. I do not think that any of us can comprehend the anguish that the family has felt, and which Aran has so movingly described in his letter, although the letter gives us an insight into the effects that each of these tragedies has had on the family and others who are close to the individuals who die. Aran also says in the letter that he was unaware that anyone could die from Wolfe-Parkinson-White syndrome.

The anguish that Aran's family has felt is also felt by four other families in this country every single week. Some people, like Levon, are aware that they have a heart condition. Others simply collapse playing sport, or, like Levon, die in their sleep. That is why this Bill is so important. We must get screening for these conditions, because, as other Members have said, they are detectable and treatable. What makes me angry is that young lives are being lost unnecessarily when treatment can be offered.

The hon. Member for New Forest, East mentioned the CRY reception that we held on Wednesday night in the Terrace marquee, at which I was honoured to meet some young people who had been screened and had received treatment, and who were now living ordinary lives and looking to the future—walking, living, breathing examples of the success of screening. The hon. Gentleman also referred to screening in other countries. In the United States, for example, it is a matter of routine that young people must go through screening before they do competitive sport, which the compensation culture there may have forced to happen. The Bill is not asking for screening of the whole population; it is asking for screening of those who are potentially at most risk. If that can be done in Italy, other parts of Europe and the United States, it must be possible in this country. The Bill proposes a proactive approach, and if we do not introduce that in this country, the same numbers will continue to die each week of what are treatable conditions.

I also want to stress the importance of publicity, to which my hon. Friend the Member for Sheffield, Heeley (Ms Munn) referred. It is important that we publicise the conditions and where to get information on them. I also pay tribute to CRY for the support that it gives to

families and for raising awareness. If today's debate does nothing else, I hope that it puts this matter on the national agenda. As someone said earlier—I am remiss in not remembering whom—if all these people were dying at once, and we collected the figures nationally, there would be a national outcry to get something done. I am determined to keep campaigning to highlight this tragedy, which affects too many families.

I pay tribute to the CRY charity for its campaigning work, and particularly to the tireless work of its chief executive, Alison Cox. She can be a demanding individual on occasions, but this is an issue about which she feels passionate, and it is a credit to her and the families involved that we are getting some publicity and some progress in terms of research and getting something done. I must also give credit to them for the funding being raised for research and the screening that is being introduced across the country. They have also—because Alison is not someone who goes away easily—battered the door of the Department of Health, and a grant was awarded last year that has gone a long way to help to set up a network of bereavement counsellors who can give support to those who have lost young people in this way. That has been a good use of the money, and has provided support to many people who, as my hon. Friend the Member for Sheffield, Heeley was saying, do not know where to go to get support.

Reference has already been made to the all-party group on cardiac risk in the young, and I give my thanks to the hon. Member for New Forest, East for his support, to my hon. Friend the Member for Stockton, South for her work with the group, and to all Members who have supported us since we have been in existence. Keeping up the pressure and keeping the momentum going will make sure that we get this subject to the top of the political agenda, that we get funding for research, and that we get the screening for which the Bill calls.

Let me return to where I began, with the tragic death of Levon Morland. The hon. Member for New Forest, East pointed out that many families in tragic circumstances gain strength through campaigning and fundraising. I pay tribute to Jeff and Sandra Morland and their family and friends, who raised more than £70,000 in Levon's memory to fund research and screening. It would be remiss of me, and I would be chastised by my hon. Friend the Member for Stockton, South, if I did not also mention Jack Doyle, a former trade union colleague of hers and mine, who has worked tirelessly with the Morland family to raise money at charity events throughout the north-east. Through that association he has been of great assistance to CRY.

When I was elected to Parliament, I said that it was a very humbling experience. Coming face to face with people such as Jeff and Sandra Morland, who have lost young ones, is far more humbling. Nowadays, many people ask politicians whether we can make a difference by being here. Today this Bill gives us an opportunity to make a difference—not just to honour the memory of individuals like Levon Morland, but to give the chance of life to thousands of young people who, but for our intervention, would not have a future.

12.21 pm

Mr. Martin Caton (Gower) (Lab): It is a great pleasure to take part in such an excellent debate—excellent because it is built on the real experience of Members' constituents and people whom they know. We have even heard of the personal experience of the hon. Member for Cheltenham (Mr. Jones). I am not sure that I would want to go through what he did just to make my Chief Whip nicer to me, but I suppose it is an option I could consider.

Mr. Kevan Jones: It would not work.

Mr. Caton: I suspect that my hon. Friend may be right.

I congratulate my hon. Friend the Member for Stockton, South (Ms Taylor) on her success in the ballot, on her choice of subject, and on the lucidity and passion with which she explained the Bill's content—the reasons for it and what it would mean for all our constituents—in her detailed and exhaustive speech. I must confess that, until four or five years ago, I did not realise how many apparently healthy and fit young people were taken by sudden cardiac death every year in our constituencies.

Then I met my constituent Mrs. Paulette Smith, the local representative in the Glamorgan area for the organisation which, as we have heard, has done so much valuable work nationally and locally. She told me of her experience of losing her son Christian suddenly and tragically to an undiagnosed heart condition. He was 24. The terrible anguish that she, her husband and other family members suffered is sadly being repeated all over the country almost daily.

As we have heard, between four and eight youngsters die from cardiac abnormalities each week in the United Kingdom. As soon as Paulette learned of my hon. Friend's choice of subject, she contacted me again and urged me to give the Bill my full support. She and her husband were here at the CRY reception on Wednesday evening, and were delighted to observe the breadth of support from Members throughout the House.

It is only really at the personal, the human and the family level—as in the case of the Smiths and others of whom we have heard today—that we can even begin to perceive the real consequences of sudden death syndrome. To lose a child, even if he or she has grown to adulthood, is every parent's worst fear. It turns the natural sequence of life on its head. It is the disaster that people dread, and it must be the most difficult loss to come to terms with, whatever the circumstances. Sudden death syndrome, however, adds a further cruel dimension. It comes out of the blue and targets the apparently fit and healthy—especially the sports enthusiasts whose families are sure that their very athleticism is the best possible way of protecting their health. But in fact, because there is an undetected underlying cardiac abnormality, the stress that their sport puts on their heart can be the trigger that leads to death. A huge chasm thereby opens in the life of another family, without even the hint of a warning, and often with no opportunity for final contact with the young victim before their death. As one mum who lost her 19-year-old son put it, "The worst thing about sudden death syndrome is that there are no 'goodbyes' or 'I love yous'; the person is just taken away from you."

Those of us who have been fortunate enough never to have suffered such a tragedy can only begin to imagine its awfulness, and whether or how, over time, we could come to terms with it. Like others, I want to pay tribute to CRY for creating a network of trained

counsellors throughout the country, and to the volunteers who have themselves suffered the loss of a close relative, and who are prepared to share their experiences in helping others to cope with a similar loss. That takes a special sort of courage and dedication that we should all acknowledge.

My constituent Paulette is such a counsellor. Like other CRY activists, she is also a fundraiser for necessary medical equipment, a campaigner for improvement, and an educator about the various causes of cardiac arrest in the young, and what can be done about them. I am one of the beneficiaries of that educational role. Although I am still somewhat ignorant, I am not half as ignorant as I used to be, thanks to the CRY information that Paulette has provided, which is clear, succinct and accessible to the layperson.

Sudden cardiac death is defined as

> "an event that is not traumatic, non-violent, unexpected and resulting from sudden cardiac arrest within six hours of previously witnessed normal health".

The majority of young sudden deaths are due to inherited forms of heart muscle disorder and irregular heartbeat. My hon. Friend the Member for Stockton, South described the most common of those conditions in her opening speech and I shall not repeat them. The Bill is about screening for those conditions. We know from past ministerial answers that the Government are not convinced that a national programme is justified, because of doubts about a clear means of defining cases of such diseases and the ability to offer a prognosis on the basis of that definition, and because of a lack of evidence that such a programme would make a real difference to health outcomes. I represent a constituency in Wales, and I have received similar replies from the Health Minister in the Welsh Assembly.

On looking at the list of conditions responsible for these deaths, it appears that in most cases they can be detected using electrocardiography and echocardiograms, as has been mentioned. And there is undisputed evidence of the heritability of such conditions. It appears that if they are detected, remedial action can be taken in the majority of cases. As has been said, treatment could involve drugs such as beta-blockers and diuretics, surgery, or implanting a pacemaker or an implantable cardioverter defibrillator. Often, it would involve a change in lifestyle.

There is strong evidence that screening is worth doing, but the Bill is not calling for a national programme such as that in Italy, where all young competitive athletes are now screened. I look forward to the day when we have such a screening programme, but I recognise that it is not on today's agenda; and when it does arrive, it is unlikely to do so in the form of a private Member's Bill. The Bill does not go that far, but it is an important step forward. What it does provide is a means of turning the Department of Health's current good intentions into practical action for more of the people who are at greatest risk from these conditions.

Currently, the DOH has adopted the UK National Screening Committee recommendation, which advises that

> "relatives of people who have died of sudden cardiac death or who are diagnosed with one of the underlying conditions should be screened because there is a genetic component in many of these cases."

Unfortunately, this advice is nowhere near as widely available as it should be; nor is it regarded with sufficient urgency and seriousness. No real process is in place to ensure that it is followed.

Ms Dari Taylor: My hon. Friend is making an incredibly persuasive speech that focuses on the value of screening, but there are certain factors that should be acknowledged in terms of the UK National Screening Committee's consideration of screening requirements for cardiomyopathies and ion channelopathies. Through the Bill, we are requesting that someone be able to listen to such problems in detail on the echocardiogram, or to see them through the screening process. We are talking about often very small indicators, and specialist have to know what they are looking for in order correctly to define the condition and the treatment that should be provided.

Mr. Caton: My hon. Friend is absolutely right, and her Bill will help to correct some of those omissions. It will create a chain of responsibility for getting the necessary information to the people whose lives it might save. That chain might start with the pathologist who carries out the post-mortem and go through GP to the family members, who can then consult the relevant specialist, or it might start with the specialist who, having diagnosed cardiac disease, can provide the patient with the necessary information for her or his close relatives.

Whichever way it works, the respective responsibility of GP, specialist and pathologist would in future be clear. I have no doubt that that would result in many more people becoming aware of their need to be screened and undertaking that screening. Those who screened positive for any of the conditions could then access the best treatment, and then make the necessary lifestyle changes.

I am convinced that this simple measure can make a real contribution to reducing the death toll of youngsters in our country from sudden death syndrome. We need action now.

12.31 pm

Huw Irranca-Davies (Ogmore) (Lab): First, I pay tribute to my hon. Friend the Member for Stockton, South (Ms Taylor). Her Bill is timely. Indeed, it is overdue. Hon. Members have paid a great tribute to it, as has CRY, which also recognises the importance of the measure and the fact that it is overdue. I was at the reception earlier this week with CRY and met some old friends from Swansea who had suffered the appalling distress of a tragedy in their own family that had come like a bolt from the blue, with no opportunity to say their goodbyes to their sons and daughters. So many hundreds of people have been through that, and we all recognise the importance of the provisions and the spirit of the Bill.

Much lobbying has gone on, including by the all-party parliamentary group. I am not a member of it, but I recognise the significant work that it has done. As my hon. Friend the Member for Gower (Mr. Caton) said, hon. Members often face criticism about what we can do or what we are here for, and people ask what this democratic institution is all about, but here today, in these few hours, we can make a significant inroad into a specific area that will make a measurable difference to the quality of life of individuals and their families in dealing with what can be a great tragedy. I hope that we will hear words of encouragement from the Minister, and that we can show that this democratic institution is alive and well and functioning as it should.

Earlier, we heard definitions of who is young. While I am perhaps speaking for the young, I cannot say that I am speaking as one of them, which is extremely regrettable, so perhaps we can revisit the definitions in the Bill. The truism is often referred to that no parent, in an ideal world, should ever see their children pass away before them. I say that as the father of three young children. No parent should have to outlive their own children, but it happens.

Sometimes there are tragic circumstances. I hope that the House will forgive me if I digress slightly to pay my condolences to those affected by the extreme tragedy that we saw out of the blue sky yesterday in Madrid. The heartless and callous nature of the bombings, which snatched people away from their families, was shocking. That tragedy also draws attention to an aspect of today's debate. Although there will always be calamities that befall any family—things that happen out of the blue and cannot be predicted—all hon. Members present today are attempting to deal with aspects of life that can be predicted and detected. We are trying to introduce a measure that in some small way will, if not save all the lives of people whose conditions can be detected or improve every aspect of cardiac problems that can be diagnosed, nevertheless help in the majority of cases. That is why it is vital to respond favourably to the Bill today.

The Bill is modest, and I say that in the best sense of the word. First, it is genuinely modest in that it is not designed to provide wholesale wall-to-wall screening of every individual. It is about targeting those at the highest risk, which is surely not an unreasonable demand. Another aspect of the Bill's modesty is the necessity to inform those most likely to be at risk on the genetic chain as a result of the findings of a coroner's report. That is not unachievable or unreasonable: it is a modest aim, but it could have major ramifications and potentially save hundreds of lives each year. It is not a blanket prescription or a blunderbuss approach, but a well targeted and modest allocation of resources to achieve its ends.

If I may go beyond the Bill, there is a great need, as has already been mentioned today, for improved recognition at an early stage of certain conditions. Our GPs and clinicians do a fantastic job in all our communities, and we all know that they are extremely stretched. We see how they are trying to modernise their facilities and way of working, by bringing additional services within GP practices, joining together as GPs in order to enhance specialisms, using practice nurses and so forth. However, as has emerged time and again in the debate, somewhere along the line there is a breakdown in the clinical recognition of conditions at a sufficiently early stage.

I understand that that is beyond the scope of the Bill, but it sends out a clear message. As our clinicians and GPs rightly undergo regular updating of their medical expertise and knowledge, we now know of one issue that should be at the forefront of their ongoing training. We must also address the problem associated with the willingness to refer, which goes beyond the ability to detect when a referral for screening is necessary. It is hugely regrettable—it could lead to loss of life—when a patient is told not to worry about a condition or that it is perfectly normal, with the implication that screening is an unnecessary waste of resources. That is unacceptable. Those issues go beyond the Bill's scope, but the Bill will, in a modest and practical way, allow early detection and early referral, which could improve the quality of, or even save, hundreds of lives.

The Bill's first three humble clauses effectively set out three ways to save lives. Clause 1 deals with

> "action to be taken following a sudden death";

clause 2 refers to

> "the role of the GP";

and clause 3 refers to

> "the role of the specialist".

It is an extremely slim Bill, but those three measures alone will be enough to send a clear message to those who have lobbied hard for targeted screening that there are three simple steps to saving many lives. One issue that has emerged from our debate is the value of knowing about coronary or other medical problems. I can say that from my own experience as a sufferer of acute ankylosing spondylitis, which is a form of arthritis. It can be extremely debilitating. People in the advanced stages either have a sergeant major-style straight spine or are bent over double. The condition also has an effect on the arterial system and the lungs. I started having symptoms in my late teens, but I was not diagnosed for 10 years because of a lack of awareness of the disease, even though it affects many young people. However, the fact that I am aware of it means that I have adapted my lifestyle accordingly. I hope that the measures that I take, which include moderate exercise—despite the MP's lifestyle—and diet, will mitigate the disease's worst excesses as I grow older. It is vital that I know about my condition, and I agree with the hon. Member for New Forest, East (Dr. Lewis) when he took issue with those who claim that people would not want to know if they had one of the conditions that we are discussing today. There are issues with life insurance and other factors, but if a diagnosis is not made people live in ignorance and their lifestyles can contribute to the problem. Early diagnosis and screening are vital.

The hon. Gentleman referred to the family of Mark Cox, the tennis player, which reminded me of my father who, as a teenager at the outbreak of the second world war, applied to the Royal Air Force. He had ambitions to serve his country as a fighter pilot, but he was turned down because he had a cardiac problem. It was of a sort that would not necessarily affect his longevity—he is still going strong, and all credit to him—but he should not be exposed to the exhilaration, adrenaline and altitude experienced by a fighter pilot. That

cardiac problem was discovered by chance, and we have heard similar stories today of cardiac problems being diagnosed through chance or serendipity. That is not good enough. We need more focused, targeted action. We can identify those at most risk directly, and through them members of their family members who may be at risk. We need to do that.

The mention of Mark and Steven Cox was interesting because my father did not give up exercise after his diagnosis. Instead, he went on to captain the successful Goworton lawn tennis club for many years, and he was the club's first ever secretary. I mention that only because the history books of the club do not mention it, so I shall put it on the record here.

It is often remarked that cats have nine lives. We are not trying to give people an additional life, but to enable them to make the most of the life they have. We are trying to save lives and, by detecting problems early, to increase the chance that people can improve their quality of life. That is an admirable intention, and it is an admirable Bill. I hope that my hon. Friend the Minister will be able to encourage us that we are on the right track and can move forward with the Bill.

12.44 pm

David Wright (Telford) (Lab): I had not intended to make a contribution today, but I was so moved by some of the speeches that I have heard that I felt that I should make some remarks. My hon. Friend the Member for Stockton, South (Ms Taylor) did a fantastic job in introducing the Bill. Since my election to this place, whenever I meet my hon. Friend in the corridors of power she always has a smile on her face and something positive to say. She is one of the best and friendliest Members, and I congratulate her on her Bill and, indeed, on her whole approach to life.

People like me, who survive on a diet of Benson and Hedges, fish and chips and lager, know that we are probably heading for trouble with our health, but that is our choice. The big problem for people affected by sudden death is that they have no opportunity to make such lifestyle choices; they are struck down at a young age by terrible circumstances, which have enormously traumatic effects on their families and friends. That is what the Bill is all about. It will offer screening to the families of people struck down in those circumstances, so that the rest of the extended family has the opportunity to avoid the desperate and terrible effects of further loss.

The Bill is about changing the law, or exerting sufficient pressure on the Department of Health, to prevent unnecessary and untimely deaths. As my hon. Friend said, some of the case studies are truly shocking: five deaths in one extended family; repeated misdiagnosis as epilepsy or asthma; and people found dead in their bed after doctors had dismissed their condition as no more than "a nuisance".

If successful, the Bill would enhance the screening process and establish an automatic right to screening for all relatives of the victims of sudden cardiac death and all those diagnosed with symptoms of the syndrome. By raising the profile of sudden cardiac death, the Bill would at least encourage doctors, patients and screening technicians to take the issue seriously in future.

In her exhaustive speech, my hon. Friend outlined the scale of the problem. A minimum of four, and probably more than eight, apparently fit young people die every week, and those deaths are preventable. At present, the Department of Health adopts the UK National Screening Committee recommendation, advising that

> "relatives of people who have died of sudden cardiac death, or who are diagnosed with one of the underlying conditions, should be screened because there is a genetic component in many of these cases".

However, that leaves the following problems, resulting in the sudden premature deaths that we are talking about. First, the Department of Health recommendation lacks any sense of urgency in terms of action, or any indication that such conditions could be fatal. Secondly, the advice is not known as widely as it should be among doctors or patients. Thirdly, the screening process itself is problematic; frequently, the technicians and medics who perform screening have not been trained to look for the conditions that could lead to sudden cardiac death. We need to build up greater awareness of the issues.

The Bill will significantly improve the process and availability of screening. It aims to ensure that pathologists recommend screening for the first-degree relatives of young cardiac deaths, or suspected young cardiac deaths. Those relatives will be able to claim screening as a right.

The Bill is all about choice. I mentioned the problems with my own diet, but that is the choice I make. The Bill gives the families and extended families of the victims of sudden cardiac death a choice. We have heard today that some people do not want to know that there could be a problem in their family, or that they could suffer sudden cardiac death. That is their choice, but they need to be given the opportunity of proper screening.

Those who have exhibited signs or symptoms, including fainting, palpitations or repeated black-outs, can claim screening as a right—as can their families. The Bill will ensure that, when heart screening is carried out, it includes the factors associated with sudden cardiac death in the young.

As has been made clear throughout the debate, there will not be a national screening programme. I understand that such a programme was rejected following the 1999 Logan report, which was commissioned for the UK National Screening Committee. So that is not what is being proposed today. We are talking about targeting action on those who need it the very most and offering a choice to those people to take that screening opportunity if they desire to do so.

I want to touch briefly on what the Government have achieved in relation to coronary heart disease. We have talked a lot about gaps in services provision today, and anyone listening to the debate or reading *Hansard* would think that the Government have not been doing much in relation to health services. In truth, the Government have done an enormous amount, and I am incredibly proud, as a member

of the Labour party, of the significant investment that the Government have put into health care services. Certainly, the record on coronary heart disease is extremely good.

The Government's priorities have been to improve access to services across the patient pathway and to increase rapid choice for patients by achieving the two-week standard wait for rapid access chest pain clinics, setting local targets to make progress towards the national service framework goal of a three-month maximum wait for angiography and delivering the maximum wait of three months for revascularisation by March 2005, or sooner if possible.

We need to reflect on some of the figures. The number of heart operations carried out each year has risen from 40,983 in 2000 to about 56,000 in 2003. The NHS target plan to carry out 6,000 extra heart operations by 2003 was met a year early—significant progress in respect of coronary heart disease. No patient waits more than nine months for heart surgery, compared with 2,700 patients doing so in March 2000. Since July 2002, patients waiting more than six months for their heart operation have been offered treatment at other NHS or private hospitals. Latest information—that for 2002–03—on coronary heart disease mortality rates shows a 23.4 per cent. reduction against the 1995–97 baseline. So we are making significant progress in dealing with coronary heart disease.

Of course the difficulty is that the action tends to be targeted on those who are older and those who have a problematic lifestyle—a little bit like my own. Let us see what happens to me over the next 20 or 30 years. I hope that I do not get into the situation that the hon. Member for Cheltenham (Mr. Jones) talked about so movingly. Perhaps I should change my ways now. We are talking about young people who die suddenly, although they often appear to be very athletic and social, going out nightclubbing or doing a range of other activities, and they are not targeted by the NHS.

Huw Irranca-Davies: The impact of exercise on those who are particularly vulnerable to such conditions has been repeatedly mentioned during the debate; but, for balance, will the hon. Gentleman emphasise the importance of well moderated exercise where that can be done? That is a crucial aspect to consider, and I would not want hon. Members to leave the House today thinking that we were constantly attacking exercise per se.

David Wright: My hon. Friend makes a very important point. Indeed, I try to walk up the stairs of Norman Shaw South daily, which is probably the only exercise that I ever get. It is important that we encourage people to exercise, and by encouraging a screening programme, we are certainly not telling people that they must never take any exercise, or go for a cycle ride or a long walk, once they have been screened. The opposite is probably true: we are asking them to understand the regime under which they are operating and to realise how their diet and general level of physical exercise affects their well-being, but to beware of the possible problems. That involves promoting and encouraging understanding. The last thing that we would want to come from such a debate would be a message to discourage people from taking part in physical exercise. That is not what the Bill is about at all. As other hon. Members and I have said, this is about choice. People can decide not to be screened if they want to. The Bill is very much about giving people an opportunity to make an informed choice.

On facilities to promote better cardiac rehabilitation and physiotherapy, we have done some excellent things in my local hospital in Telford, which has fully refurbished its gymnasium. David Platt, the former England player, reopened the facility about six months ago. It is superb; all the kit is new and has been designed to help people who have had heart problems. Such facilities can be made available to people who have been screened and have realised for the first time that they may have a problem. We could see exercise programmes designed to help and support them, professionally put together by the staff who have been involved in screening them. What we have seen happen in my local hospital is very positive. We are developing more facilities that are funded publicly and by the friends of the hospital to try to assist and support people with heart problems.

As I said, the emphasis seems to be placed on older people. We must shift the emphasis away from older people and talk about the whole life cycle, however, and about encouraging people to behave properly throughout their life cycle and to understand where they are in terms of their physical health.

Ms Dari Taylor: I am grateful that my hon. Friend has come to that point. I have asked this morning for equal treatment without ageism, so that all conditions are treated equally in the national health service and are recognised as such.

David Wright: My hon. Friend is right. I entered the House as a Labour Member because I believe in equality. One of the objectives of the Bill is to promote greater equality, and that is clearly something that my colleagues and I would want to do as Labour Members. Nevertheless, I know that there is a commitment across the House to ensuring that we promote equality in such issues, and we all want to encourage people of all ages to examine issues relating to their physical fitness and well-being and to construct lifestyle programmes that suit them.

Huw Irranca-Davies: Does my hon. Friend agree that, with regard to giving a strong voice to health issues that affect the young, one of the most effective mechanisms is for young people to engage, if we can persuade them to do so, in the democratic positions that are available on primary care trusts or on local health boards in Wales? The more representation that we have from people who are concerned with the youth agenda in health, the more that the pressure points can be brought to bear.

David Wright: My hon. Friend is right. We need to encourage a wider showing of people from different age groups, genders and communities—of course, the black and minority ethnic community comes to mind—on PCT structures. There is under-representation among young people, and I hope that we will see more come forward.

I pay tribute to CRY, which has been mentioned a number of times. I did not know much about the organisation until my hon. Friend the Member for Stockton, South approached me with regard to the Bill. I have visited its website, and I have taken a look at the material that it produces. The website is one of the best that I have visited in recent times. It provides a raft of information about sudden death among the young and lists a range of sponsors. For example, I think that Sir Steve Redgrave and Ian Botham are listed as supporters of the organisation. I encourage people to take a look at the site and to start to understand some of the important issues a little more

closely. I would like to see more young people engaged and involved with primary care trusts. Perhaps organisations such as CRY can promote and encourage young people to participate more effectively, and can be another tool that we can use to engage people more generally.

We also need to consider programmes to support people who are first responders when others find themselves in difficulties. An excellent first responders programme has been promoted by the Government, I think in partnership with St. John Ambulance and other organisations. We may need to raise awareness among such organisations of the fact when people see a young person struggling or in trouble, sudden death may occur, so they need to be trained effectively to understand the symptoms that are involved and the processes that are needed to get the patient into care very quickly. Obviously, the people who have symptoms are the lucky ones in many cases, as they are the people who get to be screened and have their situation examined. The most unlucky ones are those who die very rapidly. Such deaths might be avoidable and preventable if an awareness that there was a history of such conditions in somebody's family meant that screening would take place.

In conclusion, I have great respect for my hon. Friend the Member for Stockton, South, who gave a detailed explanation—I confess, however, that it was difficult to follow—of the circumstances surrounding sudden cardiac death in young people. It was a fine speech, and I congratulate her on it. I wish the Bill all the best, and I hope that the Minister's response will allow it to make significant progress. Once again, I congratulate CRY on its work in this important area.

1 pm

Dr. Vincent Cable (Twickenham) (LD): I, too, congratulate the hon. Member for Stockton, South (Ms Taylor), and offer Liberal Democrat support for her Bill. I do so both as party spokesman and in a personal capacity, as I was flattered when she asked me to be a sponsor. We wish the Bill well.

The hon. Lady has done an enormous amount of research on the subject, and she introduced the Bill with a great deal of conviction, which everyone found compelling. Our debate has been characterised by the emotionally compelling cases made by the hon. Members for New Forest, East (Dr. Lewis), for Brentwood and Ongar (Mr. Pickles), and for North Durham (Mr. Jones). Perhaps the most compelling case was made by hon. Friend the Member for Cheltenham (Mr. Jones), who spoke from his own experience, thus adding a great deal of weight to his analytical arguments and making the debate better and stronger.

The arguments in favour of the Bill can be summarised as a mixture of elementary humanity and good economics. Elementary humanity comes into play because we are talking about young people who die prematurely, often in tragic circumstances. The legacy for their family, parents, brothers and sisters is the deeply painful knowledge that their disease was both detectable and treatable. The fact that it was neither detected nor treated generates guilt and anger, which is a powerful humanitarian case for doing more and, as several Labour Members said, collectively making a difference. The good economics stem from the attractiveness of basic preventive medicine and screening. We should detect disease early and apply recognised therapies through drugs and surgical intervention, which are relatively low cost, as an alternative to the painful, prolonged and intensive treatment described by my hon. Friend the Member for Cheltenham, which, as he said, is an enormously costly use of resources. Humanity and economics therefore come together in a way they rarely do.

We should consider why it has fallen to the hon. Member for Stockton, South to tackle the issue in a private Member's Bill. It is clearly a good private Member's Bill, because it is modest and makes no claim on public resources—indeed, it may save the Chancellor a great deal of money—but why was it necessary to pursue the issue through that channel? The hon. Members for Ogmore (Huw Irranca-Davies), for Telford (David Wright), and for Gower (Mr. Caton) all addressed the defects of the current system, and I shall add two observations, one of which has not been made before. There is a general problem securing attention in the health service for difficult and obscure conditions that need specialist treatment. Every year, 200 to 400 individuals die of such conditions, but as has been said, that is a large number for the people who are affected. In the greater scheme of things, by comparison with deaths from cancers and the main heart diseases, the number is small, so those specialist conditions slip through the cracks. I am involved in all-party groups on pulmonary hypertension and on motor neurone disease, specialist conditions that have no connection with the illnesses we are discussing today but which share the problem of commanding insufficient attention to get a national service framework. Primary care trusts are overstretched, so it is difficult to get local attention as well. There is a general problem with getting the attention in the NHS that those deeply troubling but essentially minority conditions demand.

The hon. Member for Telford dealt admirably with the other underlying reason why we need such a Bill—the existing system is not working very well. The hon. Gentleman set out the reasons. Although there is screening, it is not proactive. There is no pressure on the pathologist conducting a post mortem or on the GP to do anything, so nothing necessarily happens. Something needs to be done through the modest provisions of the Bill to inject a greater sense of urgency and importance into the processes that are already occurring.

Huw Irranca-Davies: I thank the hon. Gentleman for giving way, and for his intelligent analysis of what is satisfactory and what is not. Would he join me in applauding the simplicity of the proposal that a pro forma should be attached to the post mortem report where the cause of death cannot be identified or the cause of death could be identified as a cardiac disease? The simplicity of attaching a pro forma to that diagnosis which the doctor could follow up is bliss indeed.

Dr. Cable: Yes, and I thank the hon. Gentleman for reinforcing the point. One of the criticisms frequently made of us in the House is that, often for the best of reasons, we generate additional regulation and red tape. The Bill clearly does not involve that. It calls for a simple, straightforward procedure to which nobody could possibly object. I expect the people involved would be grateful that a standardised approach would be required.

The Bill is desirably modest because there is a general consensus that indiscriminate screening would not be helpful. Reference was made to the Logan report.

National screening that was imperfect and covered enormous numbers of people when only a small number are affected would generate a large number of what clinicians call false positives and false negatives, causing anxiety on the one hand, and on the other hand missing many cases. Nobody who has spoken in quite a long debate has advocated a mass screening programme. We are dealing with a specific and commendably simple approach.

I shall pose a few questions, which the hon. Member for Stockton, South or the Minister may be able to answer. Part of the purpose of the debate is to exercise critical scrutiny. We are all in favour of the Bill, but there are questions that need to be asked. The first question I would ask is how many people or what percentage of the people who are affected by the conditions—there are about seven conditions—are being picked up under the present system? Are we talking about 10 per cent. or 50 per cent.? I have no idea, and nobody has used numbers.

What percentage is the hon. Member for Stockton, South aiming for as a result of her provisions being introduced? I suspect that is not a question she can easily answer, but it would give us an indication of how much good we were doing through the Bill. In his intervention, the hon. Member for New Forest, East (Dr. Lewis) cited the case of Germany, where I think he said roughly four times the number of people were undergoing surgical procedures as a result of the screening techniques there. Is that the scale of the improvement that we can expect?

The second question is how many people would be cured as a result of being identified through screening. The hon. Member for Ogmore commented that knowledge in itself is desirable, and it may well be, but it would be much better if people were cured. I am not a clinician and I do not know the medical arguments, but it would be useful to know roughly what percentage we would expect to be cured if more people were identified through a better screening system. What would the ultimate human, medical and economic benefit therefore be? The other side of the question is how many people would still not be picked up. I read through the medical paper that was background material to the Bill and I did not understand a great deal of it, but I got the impression that, of the seven conditions, some were hereditary but some were not. How many people would still not be picked up, even as a result of a more sophisticated screening system?

Another question to which I should be interested to know the answer is this: will there be any attempt to collate the information to create a national database? This is a decentralised initiative that very much depends on the initiative of the pathologist and the GP. Is it possible to disseminate their knowledge? That matters in terms of adoption, for example. In my own family, one of my cousins was adopted at birth with the terrible condition of Huntington's disease because there was no mechanism for sharing information about risk. Is there any way of putting information about people who are identified through screening, but do not follow it up or pass it on to their families, on to a database so that it can be more widely used?

My final question, which was touched on briefly by the hon. Member for Ogmore, concerns insurance. Has the hon. Member for Stockton, South talked to the insurance industry about the implications of more effective screening? As more people will know that they are at risk of a fatal disease, does that mean that they will automatically be blackballed from life insurance or pay heavier premiums for it? Would that penalty disappear if they had been treated with drugs or through other interventions? The issue involves all kinds of difficult ethical and economic problems that have been addressed in larger fields such as cancer.

My questions are not intended to be destructive, but to find out a little more about the background. I, like other Liberal Democrat Members, strongly support the Bill and hope that it will complete its passage. We wish the hon. Lady well and hope that through these proceedings we will have made a small difference to the lives of our constituents.

1.11 pm

Dr. Andrew Murrison (Westbury) (Con): I congratulate the hon. Member for Stockton, South (Ms Taylor) on introducing the Bill. It has cross-party support, which is a good start for a private Member's Bill. I also congratulate her on its simplicity. Having recently spent some weeks navigating the convolutions of the Human Tissue Bill, it is a joy to find a measure that makes sense on first reading it.

I think that my hon. Friends felt that as a medic I am well equipped to cope with the daunting list of conditions involved in sudden cardiac death. In truth, however, ion channelopathy, arrhythmogenic right ventricular dysplasia, hypertrophic obstructive cardiomyopathy and the rest tripped off the tongue of the hon. Member for Stockton, South as well as they can trip off mine. She demonstrated a command of a very difficult subject area and dealt with it comprehensively.

As well as the hon. Lady's speech, we heard excellent contributions from 10 Back Benchers: my hon. Friends the Member for Brentwood and Ongar (Mr. Pickles) and for New Forest, East (Dr. Lewis); and the hon. Members for Inverness, East, Nairn and Lochaber (Mr. Stewart), for Cheltenham (Mr. Jones), for Sheffield, Heeley (Ms Munn), for North Durham (Mr. Jones), for Gower (Mr. Caton), for Ogmore (Huw Irranca-Davies), for Telford (David Wright) and for Twickenham (Dr. Cable). I particularly enjoyed the speech by the hon. Member for Twickenham, who dealt sensibly with the economic benefits and disbenefits of screening, and the reasons for sometimes not screening.

In March, my hon. Friend the Member for South Suffolk (Mr. Yeo) and I, with other colleagues, tabled an early-day motion that drew attention to the fact that the range of conditions that we are debating is not given the attention that it deserves. Indeed, I could find little direct reference to it in the national service framework for coronary heart disease when I checked on its website last night. To be fair to the authors and to Ministers, for most people heart disease tends to means furred-up arteries, aschemic heart disease and heart attacks. It tends to mean the elderly and the middle-aged, not the young—schoolchildren and pre-school children or young people in the springtime of their adult life and in their physiological prime. Yet that is what we are discussing—sudden death when it is least expected, causing tragedy to families that can last for a lifetime.

We are discussing a range of conditions that are mercifully uncommon, but as has been said, they are by no means confined to the minutiae of medicine. The medical profession has some way to go in embracing best practice that it has established and in cutting the

toll of sudden death in the young. We have heard many comments about that, and I endorse them. Several helpful suggestions have been made about the way in which doctors and professionals can act to improve notification of the conditions and ensure that those who might be affected are adequately screened. Screening is in place and accessible, and it should be accessed by those who are deemed to be at risk.

On Wednesday, those of us who attended the CRY reception met several people with first-hand experience of such covert conditions. I was reminded of my cousin, David Horn, who collapsed and died in his school playground when he was 10. As is invariably the case, the event had profound and enduring consequences for David's family. For his parents and grandparents, nothing was ever the same again. That experience was shared by several people at the CRY reception.

Screening is an intrinsic part of our health care system. It begins for many of us before we are born. Heart and congenital defects are often picked up by ultrasound in utero, and screening continues with routine health checks immediately after birth, throughout early childhood and into adult life. Cervical and breast screening are routine and we now have health checks for the elderly. Most of that is driven by evidence-based research and screening for other conditions, such as prostate and bowel cancer, may be added to existing provision.

It is important that all such screening be based on the best available evidence and that we are clear that it improves people's lives, longevity and general well-being. We therefore need to be fairly directed in our screening efforts. However, the UK National Screening Committee has said that population screening is not appropriate for hypertrophic cardiomyopathy. It finds no evidence that outcomes will be affected, and the case for population screening falls, according to the Bradford-Hill criteria that govern such matters. The Bradford-Hill criteria determine whether screening is a useful test. They have been used for many years and are as relevant today as ever.

We should put aside for a moment the fact that population screening is not the subject of the Bill. In a written answer in December, the Minister appeared to confuse hypertrophic cardiomyopathy with sudden cardiac death. The former is only one of many causes of the latter and it would be instructive for the UK National Screening Committee to consider the other causes against the criteria for screening that I described. Perhaps the Minister will comment on that in her remarks, especially since we understand that the UK National Screening Committee is reviewing the evidence base this month.

It would be interesting to know what has been learned from Italy, where cardiac screening for athletes has been routine since 1971. Indeed, a certificate of fitness is needed there to compete as an athlete. Clearly, that involves school sport. I understand that our Government want to reverse the decline in British school sport in their fight against obesity and diabetes. The Minister might feel that that provides a good opportunity to dovetail nicely with adopting the Italian approach to screening youngsters. That is currently on the agenda, with the improvement of our school sports facilities. As part of that, perhaps the Minister will consider whether aspects of Italian practice might be introduced in this country. I would be interested to hear her thoughts.

In the meantime, the UK National Screening Committee and the British Heart Foundation recommend that relatives of people who have died from a sudden cardiac cause or who have been diagnosed with an underlying condition should be screened. This gives an official stamp to clinical good practice, and it seems likely that practitioners who fail to comply will lay themselves wide open to claims for professional negligence. Very few cases are brought against doctors for professional negligence in this area, and I suspect that that is because this range of conditions is not well known among the public at large. There appears, therefore, to be a very strong case for raising awareness both in the profession and among the general public.

The screening of first-degree relatives is quite straightforward, and the British Heart Foundation makes it quite clear that it should always happen. Assessing the significance of common complaints is far more difficult, however. Some of the symptoms cited in the Bill as triggers for screening are so common as to be almost universal. It is often said that common things occur commonly, and fainting, giddiness and palpitations almost always do not have a significant cardiac cause. In each case, a careful history must be taken, and I would suggest that, in the young, a physical examination will invariably be warranted as well.

I suspect that the threshold for referral for further testing is being lowered all the time. However, a GP might be quite clear that a person has simply fainted for a particular reason, for example, and in such circumstances would not consider that person to be at any greater risk than anyone else. The value of screening in such a situation is perhaps debateable. I hope that the publicity that we are generating today will help to lower the screening threshold and make doctors think very carefully about the possible cardiac origins of apparently trivial symptoms. The American and European colleges of cardiology have set out the symptoms and circumstances that should prompt screening, and doctors who ignore them are on a very sticky wicket.

The Alder Hey scandal, in which children's organs were retained as a matter of routine, rightly prompted the Human Tissue Bill, which I understand will return to the House shortly. In welcoming that Bill, however, we should be alive to drawbacks that might have been only dimly foreseen at the time of drafting, and which touch on this area. A histopathologist has written in CRY's recent booklet that, post-Alder Hey, pathologists have been somewhat reluctant to retain material that might previously have been kept for a second opinion or further tests. I think that that is understandable. The author points out that requests may come from grieving parents who are struggling to come to terms with their loss. Indeed, in my experience, such a request might come many months after the bereavement, but in future, that opportunity will be denied to them. The same pathologist hints at a feeling of professional inadequacy when dealing with sudden cardiac death, as it is often not possible to identify any structural cause. Given the uncertainty, one wonders how many other deaths with a cardiac cause are wrongly put down to epilepsy, asthma, drowning or simply the coroner's catch-all: natural causes.

In June 2001, the then Under-Secretary of State, the hon. Member for Pontefract and Castleford (Yvette Cooper), described coroners' practice in this regard as "antiquated". Will the Minister tell us what progress has been made to update it? Such updating would go some way towards addressing the concern expressed by hon. Members earlier about the true number of sudden cardiac death cases. It is important to ensure that we tighten up our diagnostic criteria, in order to get a true representative number of cardiac deaths, because at the moment the margin is simply too great.

In June 2001, the same Under-Secretary of State responded to an Adjournment debate on this subject led by my hon. Friend the Member for New Forest, East (Dr. Lewis). It was a very good debate, and I spent some time studying it last night. In it, my hon. Friend was told that the Minister would investigate the potential for using IT in raising awareness about sudden cardiac death, both among health professionals and the general public. That relates to a point raised earlier about how to increase knowledge of this set of conditions among the public and doctors, because at the moment, clearly, they are poorly understood. IT provides a good way, as the then Minister was right to say three years ago, of broadening the knowledge of that set of conditions among the profession and the public. I would be grateful if the Minister would comment in her winding-up remarks on what has been achieved in the three years since the June 2001 debate.

We know that a great deal has been achieved by CRY. We know that a simple electrocardiograph helps enormously to distinguish the worried well from patients with problems. Electrocardiography may not yet be routinely carried out in all GP premises but there is no particular reason why it should not be. Reporting can, of course, be done elsewhere, or even, these days, automatically. CRY has provided a large number of ECG machines for that purpose, which I hope will encourage doctors to investigate symptoms that previously might not have been investigated.

This Bill is unusual. Its intention is to set out primary legislation that will articulate best clinical practice. The Minister may point out that successive Governments have declined to mandate best clinical practice in this way. She may well contrast this Bill with the way in which we deal with screening for other issues. It could be said that the departure from the norm that we are discussing today could set a trend that might lead ultimately to the incorporation of large tracts of medical practice in the statute books. We would need to consider the implications of that. Nevertheless, the hon. Member for Stockton, South and CRY have constructed a good case, which is worthy of further examination. I look forward to the Minister's remarks, and I hope that she will have something substantial to say in response to the issues raised.

1.27 pm

The Parliamentary Under-Secretary of State for Health (Miss Melanie Johnson): It is a pleasure to respond to a debate of such length and quality, to which hon. Members have made many heartfelt contributions. I congratulate my hon. Friend the Member for Stockton, South (Ms Taylor) for bringing this important issue to the House's attention.

As my hon. Friend explained movingly and passionately from her personal experience and the experience of many families that she described, it is devastating for families when an apparently healthy young person dies suddenly without warning. To see young people struck down unexpectedly before they have reached their full potential or had a chance to say their goodbyes is a tragedy beyond measure for their families and friends.

First, I add my warm tributes to those already paid to the dedicated work of Cardiac Risk in the Young and the other voluntary organisations that provide a counselling network to help families recover from their loss. Support from people who have real experience and genuine understanding of the impact of sudden cardiac death can be a remarkable comfort and help to those who have lost loved ones in those circumstances.

Before I move on to the specific issue of sudden cardiac death, I want to take a leaf out of the book of my hon. Friend the Member for Telford (David Wright) and set this matter in the wider context of progress that we have already made in cardiac care generally. Hon. Members will be delighted to know that we are well on the way to reaching our targets to reduce by 40 per cent. coronary heart disease and stroke in people under 75 by 2010. The number of deaths has already fallen by more than 23 per cent. in the period 2000 to 2002, over a 1995 to 1997 baseline. Current evidence strongly suggests that that target is likely to be met as early as 2008.

Prescription of statins by general practitioners is increasing by about 30 per cent., which indicates that important work is taking place in primary care. The national service framework for coronary heart disease—mentioned by a number of Members—and the NHS plan set the target of an extra 6,000 heart operations by April 2003. It was met a year early. The number of heart operations carried out each year has risen from 40,983 in 2000 to about 56,850. Waiting times for heart surgery are tumbling. In 1996, some patients waited two years for heart operations; today, no one waits longer than nine months, and in 2005 no one will have to wait more than three months.

The patient choice scheme came into operation on 1 July 2002. All patients who must wait longer than six months for operations are now offered the option of treatment at another NHS or private hospital, or at a hospital abroad, unless there are medical contra-indications.

About 275,000 people experience heart attacks every year along with the hon. Member for Cheltenham (Mr. Jones). Evidence has shown that administering clot-busting drugs—thrombolysis—within 60 minutes of a call for professional help can save 65 lives in every 1,000. There has been a consistent and sustained improvement in the faster delivery of clot-busting drugs to heart attack patients since the publication of the national service framework just over three years ago.

Much progress is being made in the prevention of coronary heart disease. Since 2000, 3,770 people have been helped to stop smoking. GP practices are working towards the establishment of disease management registers, and are actively managing patients at risk of coronary heart disease. Money is being invested through the New Opportunities Fund to increase consumption of fruit and vegetables. We have a national school fruit scheme, which by the end of the year will give 2.2 million children in infant schools a free piece of fruit each day. We also have five-a-day programmes.

I mentioned the importance of statins, spending on which has increased to more than £500 million a year. That benefits more than 1.8 million patients, and protects them from heart attacks. Patients with established heart disease, or at high risk, will benefit from the improvements in care. More effective prescribing will save lives—more than 1,000 lives a year just from the prescription of aspirin for heart attack survivors, and 3,000 from the prescription of statins to people at significant risk.

The national service framework has led to improvements in treatment for people with heart conditions. At 110 sites, 681 defibrillators have been installed, and evidence shows that 36 lives have already been saved. The target of 6,000 extra operations was met a year early. Currently, no one is waiting more than nine months for heart surgery, compared with nearly 2,700 in March 2000. Rapid access chest pain clinics are operating in all acute trusts, giving diagnosis or the all clear to patients within two weeks rather than the months for which they used to have to wait. The Government have set explicit targets for reductions in angiography waiting times. For the first time ever, no one will wait more than nine months for angiography by March 2004.

In June 2003, there were 618 consultant cardiologists in post, and a 29 per cent. increase since 1999. The number of cardiothoracic surgeons has increased by 18 per cent., to 217, over the same period. Data from the Royal College of Physicians myocardial infarction national audit project—MINAP—show that more than 75 per cent. of heart attack victims now receive thrombolysis within 35 minutes of arriving in hospital, compared with only 30 per cent. in March 2000; 50 per cent. are being treated within 20 minutes, and 43 per cent. within 60 minutes.

Mr. Kevan Jones: What the Minister is saying is fascinating, and it is good news that a Labour Government have put extra money into the health service, but what on earth does all this have to do with the Bill?

Miss Johnson: One of our colleagues discussed developments in treatment for coronary heart disease, and such developments form the background to the Bill. My hon. Friend is not showing the enthusiasm for these matters that I would have expected. We have implemented a £582 million hospital building programme, and we are spending huge sums on cardiovascular disease, replacement catheterisation laboratories and improved standards and delivery across the piece.

In the light of all the excellent progress being made, it is easy to forget about the times when all the hard work in improving services has not made it possible to help. In most cases of sudden cardiac death, there is little or no warning, which is what makes each story so tragic. Two main conditions cause sudden cardiac death in young people: hypertrophic cardiomyopathy and dilated cardiomyopathy. Experts estimate that some four to eight sudden deaths occur each week, which equates to about 200 to 400 deaths each year. The incidence of hypertrophic cardiomyopathy—the most common underlying condition—has been estimated at one in 500 in the UK. I am sorry that the hon. Member for Twickenham (Dr. Cable) is not in his place, but in response to his question, we cannot do better than that figure in defining the numbers at risk from these conditions.

The other causes of sudden cardiac death are other cardiomyopathies and disorders of the heart's electrical conduction system that can cause arrhythmias, such as Long QT syndrome and Wolfe-Parkinson-White syndrome. The majority of people with these underlying conditions do not have any symptoms for all or most of their lives, but in a small minority of cases the condition leads to sudden and unexpected death, often in early adulthood.

Given what has been said today, I know that the whole House shares my concern at the terrible effect that such problems can have on the families affected. In recognition of that, and in order to provide further support, we are funding a three-year project run by CRY. It will offer specialist skilled support for those who have suffered the loss of a young family member through sudden cardiac death. It will also offer training as counsellors for people who have had similar experiences, and at the end of the course, fully trained counsellors will be available in all parts of the country.

CRY has called for the screening of young people to identify those with cardiomyopathy and those who are at increased risk of sudden death. It argues that screening would save lives and reduce parental anguish, and my hon. Friend the Member for Stockton, South has passionately taken up its cause. We have looked at its arguments carefully and we entirely agree that increased awareness of the disease is important, and that the careful provision of information can do much to educate the public. CRY and the other organisations concerned are very active in this regard. We also agree wholeheartedly that if young people are experiencing symptoms that are of concern—unusual breathlessness, palpitations, dizziness or fainting—it is important that they seek advice from their GP. We must also consider whether the available evidence indicates that screening is always the right course of action.

The UK National Screening Committee advises the Government about all aspects of screening policy and to inform its proposals it draws on the latest research and the skills of a specially convened multi-disciplinary expert group.

The NSC assesses proposed new screening programmes against a set of internationally recognised criteria covering the condition, the test, the treatment options and the effectiveness and acceptability of the programme. Such assessment is intended to ensure that programmes do more good than harm at a reasonable cost. While screening has the potential to save lives and improve quality of life through early diagnosis of serious conditions, it can never be 100 per cent. accurate.

The NSC is increasingly presenting screening in a risk reduction context. Its child health sub-group has advised that there is currently insufficient evidence to introduce a national screening programme for hypertrophic cardiomyopathy, the most common cause of SAD, either for the whole population or for specific sub-groups. The child health sub-group advises on all aspects of childhood screening programmes, and its advice in this case is that there should not be a national screening programme until further evidence is available.

I emphasise that the child health sub-group examined carefully the concerns about the possible negative aspects of screening and its consequences for the future employment and insurance of the young people involved. It also considered the psychological consequences of telling young adults and their families that they have a condition that might kill them suddenly, without warning. The sub-group has considered the position again in the light of recent research, but has decided that it remains the same at present.

We have concerns about the possible negative aspects of screening and whether it would truly be of benefit to young people. It is not an easy decision to take. While the meaning of a positive screening is so inconclusive, we must think carefully about whether it is fair to impose this burden on the young. The issue is not clear-cut by any means.

Dr. Julian Lewis: Is one of the sub-groups that is being considered that of the relatives of children and young people who have already died? It is inconceivable that that sub-group would not benefit from a screening programme. How many representations have been received from families wanting to know, as opposed to those from families not wanting to know about the dangers to their children?

Miss Johnson: We have already heard some anecdotal evidence about families' wishes, which I agree cuts in a different direction from the one in which the screening committee has gone.

Perhaps I can go on to say what the normal process should be for those who know that they are more likely to be at risk. The Bill asks us to standardise the screening process for all relatives of people who have fallen victim to sudden cardiac death. That could cause problems in overriding the clinical judgment of individual doctors and would be very difficult to enforce, and the House should consider carefully whether we should do that. We must support and value the autonomy and experience of family doctors, respect their skills and judgment and give due regard to their knowledge of individual patients and their ability to act accordingly. GPs should have the right to make decisions with patients and their families, and not have decisions imposed on them, as the hon. Member for Westbury (Dr. Murrison) said. We share, as GPs do, the desire for a proper follow-up of families at risk, but we believe that it must be done sensitively, with a judgment about the human realities of each individual case.

In response to the hon. Member for New Forest, East (Dr. Lewis), doctors should investigate all the close relatives, and especially siblings, of those who have suffered sudden cardiac death. That would usually include referral for a cardiologist's opinion. The practice is based on the genetic linkage of hypertrophic cardiomyopathy and some cardiac rhythm disturbances that may be implicated in sudden death.

In addition, there needs to be good evidence that early intervention can improve the prognosis—we must be able not only to identify individuals at risk but to offer them some help when we have done so. There must be the ability to evaluate the risk of death and start treatment straight away in the knowledge that it will make a difference. A review of the evidence showed, however, that there was no way of predicting the outcome from the disease on the basis of examining the heart through ECG and echocardiography testing. The most commonly used case definition—left ventricular hypertrophy on the basis of echocardiography—misses some people at risk and identifies significant numbers of people whose lifespan is likely to be no different from that of the general population.

Sadly, there is little evidence about the treatment of cardiomyopathy. Studies have shown that there is currently little evidence that starting treatment before the onset of symptoms makes a difference to the course of the disease. It is unlikely that any benefit would be gained from screening in those cases.

On raising awareness among GPs, current medical training already covers signs and symptoms of heart conditions and heart function problems such as the symptoms that are common to many illnesses. There is no new element of training that could increase a doctor's understanding of these symptoms. It is important to recognise, however, that the work of CRY and its members—

Dr. Murrison *rose—*

Miss Johnson: I am sorry, but if I am to finish, I will have to continue.

I was saying that no element of training could increase doctors' understanding of the symptoms, but their awareness and readiness to look for them is important. Hon. Members have referred to the youth of some of the individuals concerned, so the point about whether clinicians respond as they should is a good one. The work of CRY and its members has played a significant part in that matter and we need to reflect on what should happen in the future.

It is already recommended practice that, following identification of a cardiovascular disorder, GPs should consider with first-degree relatives what action might be appropriate. However, many cases of sudden adult death are symptomless and no warning signs are present for doctors to observe. Clinical experience suggests that early treatment may decrease the risk of sudden death where there is a genetic component and a strong family history of the condition. CRY itself recommends cardiac investigations where people have symptoms or where there is a family history of sudden death. I should also point out that deciding on the best way of dealing with sudden cardiac death is complicated by the fact that it is not classified as a syndrome in its own right. That is because there are many possible causes—neurological, metabolic, cardiac problems or underlying infections.

The increased investment that we have made will lead to great improvements in some respects. I mentioned earlier the 89 new or replacement catheterisation laboratories and there are improvements in electrophysiology, 24-hour heart rate monitoring and echocardiograms. Those services are particularly relevant to those at risk of sudden cardiac death, as better monitoring may lead to a better early diagnosis. We are also supporting CRY with a section 64 grant for its project to provide bereavement counselling.

On surgical treatment for certain conditions, the National Institute for Clinical Excellence is reviewing its guidance on the use of implantable cardioverter defibrillators. An ICD is a device that can be implanted within the chest wall. It monitors the heart rhythm, senses whether there may a severe disturbance in that rhythm and, if necessary, delivers an electrical impulse to stop the abnormal rhythm and allow the normal one to resume. Current guidance already suggests that ICDs should be used for patients with an inherited cardiac condition with a high risk of sudden death.

I am very grateful to my hon. Friend the Member for Stockton, South for drawing attention to a condition that, although relatively rare, is tragic in its impact on those it affects. The Bill presents the Government with a genuine dilemma. Although we fully understand the intention behind it and share the House's sympathy for the individual tragedies that we heard about today, for the reasons that I have sketched out in my response, I am reluctantly unable to support the Bill as it stands today.

The clear motive underpinning the Bill is just. It draws attention to a real problem and concerns the lives of many young people and their families. I am not therefore prepared to leave matters as they stand now. I will shortly establish an expert group, chaired by the national clinical director for heart disease, to explore thoroughly what further steps are available to us. The group will act as an advisory board on cardiac arrhythmia and sudden cardiac death, and will inform future policy development in those areas. In response to the interest of Welsh colleagues, we would be happy to include representatives from Wales in the membership of the group.

The group will be composed of external stakeholders, similar to the external reference groups that helped to create the national service framework for coronary heart disease initially. Voluntary and professional organisations, including CRY, the Ashley Jolly SAD Trust, Hearty Voices, the British Cardiac Society and the British Pacing and Electrophysiology Group, will all be invited to join.

The terms of reference of the group will include writing a communication strategy to raise awareness in primary care of the signs and symptoms of conditions leading to sudden cardiac death. It could also make recommendations about how deaths are certified in these tragic cases, which relates to the implications of the Bill for the Home Office. It is likely that the group will conclude that an additional NSF chapter is needed to cover the issues, and we would aim to publish that within a year.

We have looked carefully at the arguments presented. My hon. Friend the Member for Stockton, South, and the other hon. Members who have contributed, are rightly passionate about the cause. I am pleased that the Bill, and this debate, will lead to the formation of the advisory group. Through that group, the Bill will make a real difference in raising awareness of the conditions leading to sudden cardiac death, and has the potential to save lives and prevent families from going through the tragic experiences that we have heard about today. I hope that the actions that I have mentioned, which will be taken forward speedily via the routes that I have outlined will enable us to make progress on the intentions that my hon. Friend outlined so ably, including increasing awareness and our efficacy in identifying and responding to these tragic conditions. I hope that she will find it possible to withdraw her Bill and meet me to discuss the membership of the group and how we can make urgent progress.

1.52 pm

Ms Dari Taylor: With the leave of the House, I appreciate this opportunity to respond to the debate. Everyone who heard it will agree that all the contributions have been excellent, thoughtful and supportive. I am most grateful to all those hon. Members who have contributed.

The last part of the contribution from my hon. Friend the Minister gave me some hope that all the issues that we have brought to the House today have a clear chance of being aired in detail and in full. Those issues are not easy; they are complex and have dimensions that I could not introduce to the House today. I am not a medic, but I have a clear commitment to reducing the number of people who die from conditions that can be diagnosed and treated. My commitment was to having the issue aired and preventing more deaths, and I thought that the best way to achieve that was through screening.

My hon. Friend the Minister has offered the House the proposal that an advisory group on cardiac arrhythmia and sudden cardiac death should be established. If appropriate, such a group would write a chapter for the national service framework for coronary heart disease. That is an incredibly positive offer. I recently wrote an article on the national service framework and received glowing responses about the NSF from primary care trusts—first about the fact that there is such a national service and, secondly, because it offers a framework of understanding and can deliver services to control various illnesses and support the people who suffer from them.

I was also pleased to hear my hon. Friend say that CRY, the charity that has done such sterling work with regard to sudden death in the young, will be included in the group. That is incredibly valuable. Indeed, the articulation of the whole debate and my hon. Friend's suggestions for the way forward are profoundly valuable.

I appreciate this chance to respond to the many contributions. I am sorry that there is not enough time for me to answer in detail the important questions put by the hon. Member for Twickenham (Dr. Cable), but I promise that I shall address them and respond at another time. My thanks to the hon. Gentleman, to the hon. Members for Cheltenham (Mr. Jones), for New Forest, East (Dr. Lewis) and for Brentwood and Ongar (Mr. Pickles) and to my hon. Friends the Members for Sheffield, Heeley (Ms Munn) and for North Durham (Mr. Jones), who sponsored the Bill and gave me the confidence to put it before the House. I also thank my hon. Friends the Members for Gower (Mr. Caton), for Ogmore (Huw Irranca-Davies), for Inverness, East, Nairn and Lochaber (Mr. Stewart) and for Telford (David Wright) and the hon. Member for Westbury (Dr. Murrison) who spoke for the Conservative Opposition.

I apologise to the House for gabbling, but I am trying to speak quickly. I am most grateful for all the speeches and interventions that were made. I shall read *Hansard* with considerable care, so that I can feel even more competent to respond on the issue, should I need to do so at another time.

I conclude on that positive note. This has been a long debate and Members have been particularly indulgent to me and I am most grateful, but I now beg to ask leave to withdraw the motion.

Motion and Bill, by leave, withdraw