Scottish Cot Death Trust

The Deputy Presiding Officer (Alasdair Morgan): The final item of business today is a members' business debate on motion S3M-6542, in the name of Gil Paterson, on the 25th anniversary of the Scottish Cot Death Trust. The debate will be concluded without any question being put. I call Gil Paterson to open the debate.

Motion debated,

That the Parliament puts on record its thanks to the Scottish Cot Death Trust for the work that it has carried out over the past 25 years in supporting families in the west of Scotland and beyond who have lost babies to sudden infant death syndrome (cot death); notes that, despite the reduction in cot deaths in the 25 years since the trust's formation, 1,510 babies have died in Scotland from cot death and that Scotland continues to lose one baby every nine days to it; wishes to pay tribute to the trust on its 25th anniversary, and acknowledges the reduction of cot deaths brought about by the trust's effective work.

17:05

Gil Paterson (West of Scotland) (SNP): Some six months ago, a neighbour asked whether I would meet members of the Scottish Cot Death Trust who were seeking assistance. Although I agreed, I took it for granted that the trust, like so many other organisations, would be looking for additional resources. I was, therefore, taken by surprise that my assistance was being sought only to explore ways in which the work of the trust could be exposed to the wider public in order to make the public more aware of the unnecessary early deaths of babies and young children through cot death. The trust particularly wanted to use the date of its 25th anniversary to raise awareness of the wide range of services that it provides, hence my seeking support for the motion to be debated tonight. I put on record my thanks to those members who shifted their debates in order that that could happen. I am very grateful for that.

I can imagine nothing more devastating than the loss of a child. I remember cases in the past in which the loss of a baby or child was unexplained and the stories that were written in the press insinuated—or, even worse, accused parents of—foul play. Most of us will be aware of high-profile cases, one of which was reported not that long ago, with the media pointing the finger at a celebrity. What dire, horrific cruelty for that person to experience being accused of responsibility for the death having just lost their child and not knowing why. Even after their name has been cleared, parents in that position are left with a feeling of guilt, wondering what could have been done to prevent the tragedy. That is why the work of the trust is vital.

The trust's aims are to fund research into possible causes of cot death, to support families that have been bereaved as a result of cot death and to educate parents and professionals in how to reduce the risks of cot death. The work that is done by the Scottish Cot Death Trust has brought about a different approach from the authorities and the press, who now have some sympathy for the bereaved families and a much better understanding of the truth than they had before.
When the trust was formed, in 1985, there were 153 cot deaths a year. In the 25 years since the trust began, there has been a significant reduction in the annual number of cot deaths—it is currently 40 a year. However, that still means that we lose one healthy baby every nine days to cot death in Scotland. Cot death occurs in every part of Scotland and affects every sector of society. Although it occurs more frequently in deprived areas, more affluent areas are not safe from the heartache. Most cot deaths occur within the first year of life, but cot death can also occur in older children; therefore, sadly, it can occur wherever children are sleeping.

In the early 1990s, the back to sleep campaign was the most significant awareness campaign ever implemented, and the Scottish Cot Death Trust was instrumental in ensuring its implementation throughout Scotland. The campaign aimed to educate all parents and carers about the need to place babies on their backs for sleeping rather than on their fronts, as they had previously been advised. It resulted in an immediate decline in the number of cases of cot death and continues to be one of the most important pieces of advice for parents. However, the campaign did not eradicate cot death completely—a common misconception that is held today.

It is estimated that approximately 2,000 children are alive today who might have suffered cot death had it not been for the research and education provided by the Scottish Cot Death Trust. Over the years since its formation, the trust has provided vital support for hundreds of families throughout Scotland. The support services on offer have been further developed, and the trust today offers an impressive range of support for families that are affected by the loss of a baby or young child to cot death.

The trust's community services nurse will visit families at home, regardless of where they live in Scotland, to provide information about cot death and the services that are available from the trust. Time will be spent listening to the family and discussing the support that is available to help them to cope with their loss. A professional counselling service is available to everyone who is affected by the loss of a baby or child through cot death. The service is available across Scotland and is provided free of charge to bereaved families.

When a parent has lost a baby or child to cot death, the arrival of a new baby can bring huge anxiety that it might happen again. The Scottish Cot Death Trust's next infant support programme aims to support parents during subsequent pregnancies, after the birth, and for as long as the support is needed. As part of the next infant support programme, the trust can provide bereaved parents with a breathing monitor, on loan for up to 12 months, to offer them peace of mind with the new baby. The monitor will sound an alarm if the baby stops breathing. All parents will receive resuscitation training before receiving the monitor so that they know what to do if the baby stops breathing. The Scottish Cot Death Trust provides that service to many hospitals across Scotland.

The Scottish Cot Death Trust is involved at every level, from counselling bereaved parents to funding national and international research, all in the attempt to eradicate cot death. Members of the trust are in the public gallery tonight listening to the debate. They want the Parliament to support their campaign this year to raise awareness of the services that they provide to end cot death. They ask of us so little, and we owe them so
much.

17:12

**David Stewart (Highlands and Islands) (Lab):** I place on the record my thanks and congratulations to Gil Paterson on securing this evening's debate to mark, as we have heard, the 25th anniversary of the Scottish Cot Death Trust. I also recognise the work of Fiona Brown, the director of the trust, and her colleagues, who have made such an incredible difference to the families who have faced such a terrible tragedy.

The key objective of this evening is to raise awareness of cot death and the work of the trust during the past quarter of a century. As we have heard, one baby dies every nine days—29 children have died so far this year. Over the past 25 years, more than 1,500 children have died suddenly and unexpectedly, and no definitive cause of death can be found.

My youngest son Liam died from cot death in 1991. He was eight months old. I remember the horror and the trauma of the moment; it has never left me. A series of images are frozen in time: the ambulance; the faces of the doctors and nurses at accident and emergency; the police; and, later, the cold and remote manner of the pathologist during the post mortem. All that contrasted with the support of friends, family and neighbours, the phone calls and visits, and the hundreds of cards of condolence.

Many other bereaved parents have told me of the tremendous support that they received from the Scottish Cot Death Trust during the crucial first few months after their loss. That was certainly my experience.

As we have heard, the number of deaths has declined since the 1990s. They are now recorded as "sudden unexpected death in infancy". Such deaths can occur in every part of Scotland and in all social strata. Of course, most occur within the first year of the child's life, and can occur whenever an infant is sleeping. Twice as many boys die as girls, and second or later-born children are more at risk, as are pre-term, low-weight babies.

What can the trust do? It has invested £3 million in research and development and has educated thousands of parents and professionals about cot death and how to reduce the risk. It has a range of resources, providing support, home visiting, counselling and befriending services. I particularly highlight the important work done with apnoea monitors and resuscitation training for parents.

Of course, every bereaved parent reacts differently. Some may want contact support to last longer than others. When I met parents through the Scottish Cot Death Trust, they told me that, having received support, they were better able to support their surviving children and to search for help elsewhere, through a general practitioner or private counselling. At times of acute grief, it is easy to forget about surviving children, grandparents, aunts and uncles and, with older children, those children's pals.

I praise the trust for its case review study, commissioned in 2000, which called for a multidisciplinary approach, getting all the agencies to work together to minimise distress
to families. I understand that NHS Quality Improvement Scotland will attempt to roll that out throughout Scotland.

Losing a young, healthy baby is one of the greatest traumas that parents could ever face. For 25 years, the Scottish Cot Death Trust has been counselling, supporting and educating parents, as well as supporting the professional agencies that work with the families. Let us never forget its pioneering research work. We owe a tremendous debt of gratitude to all who are involved with the trust—the befrienders, the fundraisers and the health professionals. The work that they do is truly outstanding and makes a real difference to many families. We honour their contributions and commitments here today.

17:16

Mary Scanlon (Highlands and Islands) (Con): I congratulate Gil Paterson on securing tonight's debate, which rightly allows Parliament to thank the Scottish Cot Death Trust for the tremendous work that it has done over the past 25 years and, I hope, to raise awareness of this issue. Over the summer I spent considerable time with babies: a month ago my daughter gave birth to twins. When we look at newborn babies, we realise what a special gift they are.

With only a small grant of £5,000 each year from the Scottish Executive, the majority of the trust's funds come from donations and fundraising efforts. Over the past 25 years, the trust has invested more than £3 million in research projects, in educating thousands of parents and professionals about cot death and informing them of how to reduce the risk of that tragedy happening to them, and in supporting families in Scotland who have had to endure the heartache of losing a baby or young child to sudden and unexpected death in infancy.

The work of the Scottish Cot Death Trust has clearly had an impact. As Gil Paterson said, in 1985 there were 153 sudden infant deaths, but in 2009 the figure was 32. We should recognise and acknowledge the reduction in deaths that has taken place over the 25 years in which the trust has been in operation. It is also noticeable from the statistics that in 1985 the sudden infant death rate per 1,000 live births was 2.32, whereas last year it was 0.54—a considerable reduction.

Cot death is not a new problem. It was mentioned in the first Book of Kings, in the Bible, which states:

"and this woman's child died during the night because she overlaid it".

Views and opinions have changed but, as other members have said, sudden death in an otherwise healthy infant can still happen to any baby or young child, regardless of their family background or social status. However, studies suggest that a teenage mum is six times more likely to have a child suffer cot death than is a mum over 20. As David Stewart said, male children are twice as likely as female children to suffer cot death. The chances of a child suffering cot death also increase if their parents smoke and take drugs. All that justifies the research that the Scottish Cot Death Trust has carried out and the resources that it has allocated to research.
The Scottish Conservatives have long argued for a universal health visitor programme to improve the support that is offered to new parents and the advice and guidance that are given to them as they raise their child. Although it may not be possible to eradicate cot death completely, provision of more health visitors to assist new parents and to warn them about some of the major risks that can cause cot death would surely assist in further reducing the number of deaths.

The Scottish Cot Death Trust has published a report of some 50 pages on the pilot of a multidisciplinary case review of each sudden unexpected death in infancy. Throughout it, there is a sense of frustration at the many delays and problems that could have been overcome including, for example, the time that is taken for the Crown Office to issue guidance to procurators fiscal, the number of fiscals who frequently fail to follow instructions, the lack of meetings being organised by paediatricians a year and a half into the pilot, and the lack of a standardised policy inquiry form to allow information to be collated from the time of a child's death.

The work of the Scottish Cot Death Trust cannot be overstated. I am delighted to have been able to take part in this debate.

17:20

Willie Coffey (Kilmarnock and Loudoun) (SNP): I, too, congratulate Gil Paterson on securing this debate to coincide with the 25th anniversary of the Scottish Cot Death Trust, and the manner in which he opened it. Mr Paterson clearly feels very strongly about the subject and, of course, it will be hard to follow David Stewart's personal contribution. However, I will do my best to contribute to the debate.

We usually spend a lot of time in the chamber debating the big issues of the day and agreeing or disagreeing on just about every subject imaginable. However, in this debate, Gil Paterson and Dave Stewart have given us a chance not only to share some of the pains of the past, but to talk about hopes for the future and for Scotland's wee weans. As part of my constituency work, I have dealt with a number of families who have lost babies, so I know how devastating it can be when the parents have some explanation for their child's death. I can only imagine how much worse it must be when the death is unexplained.

In researching the background for my speech, I found the trust's website to be very helpful and informative. Back in 1986, in the organisation's early days, there were 153 deaths, or 2.3 deaths per 1,000 births. As Gil Paterson pointed out, the current figure is 40 deaths a year. That represents a significant drop of about 80 per cent, and credit must be given to the work of the trust as well as to the input from bereaved families, who have helped us to understand the reasons for these sudden deaths.

Will we be able to reduce that number further? Indeed, will we eventually be able to reduce it to zero? Perhaps we will not, but at least we now know some of the high-risk factors. As Dave Stewart pointed out, males seem to be more vulnerable, with two boys being lost for every girl. Sixty per cent are lost during the winter months, particularly in areas of deprivation, and the peaks suggest that the riskiest period seems to be when the baby is around two or three months old. Armed with that information and other
indicators, I will ask my local health board, NHS Ayrshire and Arran, whether it might be possible to try out some intervention to assist parents whose babies might be liable to those risks at those particular times. I do not know whether that it will be possible, but I will try. Such a move will prove to be well worth while if we can reduce the death rate even further.

A key strength of the Scottish Cot Death Trust, as with many other organisations, is that people who come to the trust for help can be sure that they are dealing with someone who has a real interest in their plight and is committed to helping. The trust's range of services has clearly been developed in response to the needs of families who have been affected by the loss of a baby or very young child to cot death. Obviously the provision of a home visiting or counselling service the length and breadth of Scotland is financially challenging, but how else can we ensure that parents who are affected by the loss of a baby or child to cot death get to speak to a professional adviser who really understands what they are going through?

The fact that the services are provided alongside the input of dedicated volunteers means that parents can be helped in a variety of ways as they try to come to terms with their loss. I am sure that many of those who first encounter the trust as clients are gradually transformed into active participants in supporting others, both through the befriending service and by taking part in the trust's family days. In that way, the trust's activities bring together parents and members of the extended family who are rebuilding their lives after a devastating common experience. Those links and bonds go well beyond the support that can be provided by public services and are one of the reasons why it is so important for the public and voluntary services to work closely together.

I congratulate and thank the Scottish Cot Death Trust, commend it for the work that it has done over the past 25 years, thank my colleague Gil Paterson for bringing this very important matter to our Parliament's attention and look forward to further work in this area that will lead to a greater understanding of the problem, and might ultimately allow more of Scotland's babies to survive this crucial period of their young lives.

17:25

Hugh Henry (Paisley South) (Lab): I do not think that anyone can adequately explain the joy that a parent or grandparent feels at the birth of a child, but one of the things that comes with that joy is the fear of what else might happen. I thank Gil Paterson for giving us the opportunity to record our appreciation for the work of the Scottish Cot Death Trust. That fear of what could happen overlays far too many families. David Stewart outlined very well the sheer human emotion of losing a child. He talked about the personal support that comes from so many, but also expressed the fear and horror of having to deal with a system while grieving for a child who was so eagerly anticipated.

From speaking to people who have had a sudden death in the family, I know that they often blame themselves somehow, and think that they did something that contributed to the death, particularly of an infant. They wonder whether they could have done something that would have prevented it. The work of the Scottish Cot Death Trust should and can help to assure people that these things happen, as members have said, and that they should not feel any guilt or remorse that they somehow contributed to what was
an unexplained death.

The trust has done tremendous work on research and education. I remember that, when my children were born, we had all the debates about whether we should lie them on their front or put them on their back. It is good that we now have some kind of scientific basis for saying to parents how they should proceed. However, we should not underestimate the contribution that the trust makes in supporting bereaved families. The home-visiting service provides that bit of comfort and sympathy that can come from someone who knows a bit about what has happened, but who is not immediately attached to the family.

Counselling is often underestimated. We cannot know how people will react to an unexplained death and what they might do as a result but, too often, we leave people to their own devices to grieve and to mourn and to have to suffer the consequences without their having someone there to help them through a difficult period. The contributions of the trust’s befriending service, family days and next infant support programme are inestimable. We can imagine that a person who has just been through the trauma of losing a child and who has another one on the way will wonder whether it will happen again and whether the death happened because of something that they did.

The trust has done tremendous work to help to put the issues in context and, more important, to give that human and personal touch and support that can so often make the difference to bereaved families. It has been a tremendous record of achievement in 25 years. Whatever little we can do to support it should be taken as a given. I hope that the trust continues to develop. Although it is fantastic that the number of sudden unexplained deaths has reduced, each one that still happens is a tragedy for that family and leaves a family looking for support. I thank everyone who has done so much in the past 25 years.

17:30

Dr Richard Simpson (Mid Scotland and Fife) (Lab): I, too, congratulate Gil Paterson on securing this important debate and I welcome the opportunity to discuss the 25th anniversary of the Scottish Cot Death Trust. As members said, the trust has supported many parents who have gone through the sudden and unexpected loss of a child.

In its 25th year, the trust has a great deal to be proud of. We should celebrate the massive reduction in cot deaths, which Mary Scanlon and other members reported. The research that demonstrated that it was safer for infants to sleep on their backs, which I think originated in New Zealand, has been the main contributory factor to the massive reduction. That success should be celebrated.

However, there are still some 40 deaths annually. We need to consider the residual factors, understand what is happening and see what can be done in a policy context. Issues have been raised by a number of members. One factor is that deaths are much more common in the babies of teenage mothers. It is regrettable that the policy of reducing the incidence of teenage pregnancy, which the Labour Party and the SNP have tried to follow, cannot be said to have been a great success for either party. We need to redouble our efforts to ensure that the number of teenage pregnancies is reduced.
A second factor is smoking. It is regrettable that smoking during pregnancy is still significant. I commend the initiative in NHS Tayside, which saw that it had some of the worst statistics in that regard. The board set up a scheme whereby mothers who made and succeeded in the significant attempt to give up smoking were rewarded. The scheme was criticised in parts of the media, but Tayside’s smoking cessation statistics have moved considerably. We need to redouble our efforts to ensure that people stop smoking during pregnancy and continue not to smoke afterwards.

The smoking issue is related to the third factor, which is that there are more sudden unexplained infant deaths in poorer socioeconomic groups. We must continue to consider health inequalities and look at the balance between the universal provision of health visitors, which I think that everyone wants, and a focus on people from poorer socioeconomic backgrounds. Such matters need to be addressed.

An issue that concerns me in relation to the subject that we are considering and other areas in health is that the information that is available on the web is not always the best. Much of the information on the internet is discursive and not evidence based. We need, for example, to consider—I will use the biblical term, as Mary Scanlon did—overlying: that is, sharing a bed with the child. I do not think that it would be correct to give universal advice that that is not appropriate. However, it is probably appropriate to say that people who smoke, drink, use drugs or sedative medicines should avoid the practice. I am not an expert in the field, but we need to give clear information to parents.

Members referred to what happens after the death. Many deaths remain unexplained after a post-mortem. A post-mortem is important, but it is a cold and frankly unpleasant thing to have to go through. A very close member of my family experienced a sudden infant death, and—although I was on the periphery—to go through a post-mortem with my own family was very different from doing so with parents as a doctor. Part of the reason for that was that the post-mortem was not handled in a particularly sensitive way—this was some 30 or 35 years ago. Sensitive handling by paediatricians, the police, pathologists and other professionals is important.

I commend the Scottish Cot Death Trust for its work during the past 25 years and for continuing to try to meet the challenge of further reducing the number of infant deaths.

17:34

The Minister for Public Health and Sport (Shona Robison): I thank Gil Paterson for raising the important issue of cot death and for bringing the debate to the Parliament. I welcome the many speeches that we have heard, some of them very good, and I single out David Stewart’s speech. It is difficult to share personal experiences in the Parliament, but he managed to do that in a speech that was moving as well as positive. He talked about some of the good, positive developments that there have been.

On behalf of the Scottish Government, it is my pleasure to congratulate the Scottish Cot Death Trust on its landmark silver anniversary and to acknowledge with sincere thanks and appreciation the sterling work that its trustees and past and present staff have done over the past 25 years in supporting families that have lost babies or young children to sudden unexplained death in infancy, or cot death, as it is more widely known. Any
bereavement is traumatic, but the devastating impact on a family of the sudden and unexpected death of a baby or child is heartbreaking. That is why the support that the trust offers is appreciated so much and is so necessary.

Despite the extensive research, we still do not fully understand why cot death occurs, so we cannot totally prevent it. However, we can reduce the risk of cot death tragedies happening. As several members have said, the number of cot deaths has reduced in recent years but, sadly, we still lose too many babies. Until 1991, around 90 babies a year died in Scotland; the number has gradually decreased to around 30 babies a year. Behind each of those sad statistics is a whole family devastated. Of course, much of the credit for the reduction can be directly attributed to the efforts of the trust, working with dedicated national health service staff. It is widely thought that the reduction is due to the advice that is given to parents to place babies on their backs to sleep. Several members have mentioned that.

Research and education are key to the trust's work. Since 1985, around £3 million has been invested in studies throughout Scotland and internationally to try to identify the cause of cot death. The trust has used the findings from that research to educate parents, health professionals, the police and many more people on all aspects of cot death, how to reduce the risk of it happening, and increasing awareness of how to deal with families that face devastation.

Supporting families has been and still is a fundamental aspect of the trust's work, and it continues to develop the range of services that it offers, such as the six plus one initiative, which is designed to build networks of trust among parents who have easy access to hard-to-reach groups. More recently, it has introduced home support visits, a befriending service and breathing monitors, and it has recruited nine professional counsellors throughout Scotland in the past year. Among other things, it is planning to introduce a new website with more current information and an online forum for bereaved families and parents, and an information roadshow to go across Scotland.

The Scottish Government is working with the trust on the revision of its leaflet entitled "Reduce the Risk of Cot Death: An Easy Guide". The Scottish Government has convened an expert group that comprises clinicians, health managers, representatives from the United Nations Children's Fund, the baby-friendly initiative, the trust, of course, and Scottish Government officials to update and redesign the leaflet to maximise its effectiveness in highlighting and conveying crucial information on how to reduce the risk of cot death in a clear and simple way. Perhaps some of the reflections in tonight's debate will help to inform that process. The leaflet is currently being pre-tested with parents to ensure that the messages that it contains are easy to understand. It will be issued to every new mother in Scotland following the delivery of her baby. It is vital that anyone who cares for a baby is properly informed of current preventive measures to take.

In addition to publishing the new leaflet for the trust, the Scottish Government plans to publish a variety of posters that will highlight pertinent messages from the leaflet for distribution to various locations throughout Scotland, such as GP surgeries, hospitals and community clinics. That will further enhance awareness and therefore help to ensure that anyone who cares for a baby is properly informed of the measures that they can
take to reduce the incidence of cot death.

We continue to support the important work of the trust through the provision of grant funding. The trust will receive £7,000 per year for the next three years to help it to go forward and continue to provide its services.

As well as working with the trust, we are working in partnership with NHS Quality Improvement Scotland, expert clinicians, NHS board managers, local authority social work departments and child protection teams, the police, various charities and the procurator fiscal's office to take forward the development of a toolkit for professionals that advises on sensitive and appropriate practice and support to the bereaved family in the event of a sudden unexplained death. It came through tonight that such practice does not always happen, which can be very painful in addition to the pain and shock that the family are already experiencing. That is an important piece of work.

We are also working to restart the process of case reviews following a cot death and on the collection and evaluation of national data with a view to further reducing risk. We know that the risk of cot death is higher in cases where babies are born pre-term, with low birth weight or in families where there is socioeconomic deprivation or where there are complex needs. The refreshed framework for maternity services, which we hope to publish in January of next year, places a focus on addressing inequalities in access, experience and outcomes. The Scottish Government's maternity services action group is developing guidance to support NHS boards to improve the identification and management of those mothers and babies in areas of high deprivation who are most at risk of poorer health outcomes.

I wish the Scottish Cot Death Trust continued success in the future in identifying the causes of cot death, educating the public and professionals and, importantly, supporting families who are unfortunate enough to lose a child to cot death. I applaud the work undertaken by the Scottish Cot Death Trust. Continuing to reduce the number of cot deaths in Scotland is something to which we collectively aspire and the Scottish Government will continue to provide its support where and when it can.

*Meeting closed at 17:41.*