

Carers' Health

Working for a Positive Future

**A One-day Conference, The Roxburghe Hotel, Edinburgh
Monday 6th October 2004**

CARERS Scotland

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Introduction

The issue of carers' health is becoming increasingly important and general awareness of the problems carers face has risen in recent years. The Executive has recognised that serious changes will have to take place over the next ten years if unpaid carers are to continue to make their massive contribution to Scottish society. The Care 21 project is just some evidence of their commitment to improving their carers' strategy. However, thousands of carers' needs are still not being met. This one-day conference aimed at covering some of the key debates such as the lack of investment and available training as well as the attitudes of health professionals. It was an opportunity to share best practice and to further encourage the promotion of positive health of all carers.

The delegates were drawn from across the public, private and voluntary sectors, with local government making up the largest section of the audience.

Session One: Setting the Scene

Adam Rennie, Head of Community Care Division Two at the Scottish Executive, began the day's speeches with an overview of what the Executive has achieved so far and what its plans are for the future to further improve the lives of Scotland's carers. He explained that everyone knows that the contribution made by carers is often at the expense of their own well being. He added that there should be no obstacles in their way, they should not be penalised, their health should not be jeopardised and they should not have to fight for their rights as they currently do.

Partnership is the key to the progress that has been made over the past four years. The NHS has become more pro-active and carers' voices have become louder. However, Mr Rennie admitted that the pace of change has been patchy and that the Executive is aware of this. The Executive has also recently provided local authorities and the voluntary sector with more funding. £22 million has been spent over the last three years on providing respite for carers.

In the new Mental Health Bill, and in the Community Care and Health (Scotland) Act of 2002, carers are recognised as key partners. The Executive hopes to increase regulation and training of carers and also to encourage major changes in the NHS, with the aim of providing more patient-centred healthcare. Other goals included building an information base to examine how effective policies actually are and the promotion of direct payments and independent advocacy. There is also a working group which is currently looking into whether carers are getting the support and respite they need. Mr Rennie emphasised that the role of carers can only grow in importance and that service providers, government and society would be under immense pressure without that contribution.

Tom Laidlaw, Director of Scottish Gas, outlined the company's Carers Policy. He pointed out that 12% of employees are carers and that often their responsibilities force them to leave employment, losing on average £9000 of their yearly income. Studies have shown the extreme tiredness and stress that carers suffer. The benefits of a successful carer policy include less absenteeism and increased productivity. Mr Laidlaw was keen to stress that a carer friendly employment policy makes business sense and has social benefits. Scottish Gas provides flexible working hours, career breaks, emergency leave, planned leave and also makes provision for smaller things, such as having a phone available. This makes for a sustainable and happier workforce and enables people to realise their potential outside their role as carers. Scottish Gas has also set up a carers' network which allows for the sharing of experiences.

Michael Hirst from the University of York's Social Policy Research Unit, gave a summary of his research into stress levels amongst carers and what kind of intervention is helpful. He emphasised the fact that care giving takes place in a relationship and that interventions or lack of them always affects two people. Satisfaction and stress in care giving often occur together and effective support maximises the satisfaction and minimises the stress.

Mr Hirst's research indicated that carers are generally more likely to suffer from anxiety, depression, loss of confidence and low self-esteem than non-carers. The times when carers are most at risk include;

- before the hands-on care begins
- when it starts
- at key turning points
- when caring ends
- beyond care giving.

The kinds of carers most at risk are those that live with the person they care for and those that are heavily involved. The numbers of such carers is increasing and care spells are lasting longer. The research also clearly indicated that poor health in carers leads to a breakdown of the caring relationship and increased use of hospital, residential, community health and primary care services. Mr Hirst estimated that the annual value of unpaid care in Scotland is £5 billion. The study showed that carers of stroke victims who received training were physically and emotionally healthier. He recommended an approach that meets the needs of carers in their own right, that targets those most at risk and that involves flexible tailored intervention.

Question and Discussion Session

In the question and answers session, delegates raised the issue of assessment, how will it work and will it be effective? Adam Rennie said that it is early days and that the Executive is still investigating the best way to implement assessment. Other delegates expressed concern over the lack of consultation of carers by health boards and local authorities when decisions about a patient are being made. One delegate asked what 'participation of carers as key partners' actually means. Mr Rennie responded by saying that it depends enormously on the circumstances, but participation can take many forms.

Session Two: Challenging Preconceptions

Professor Rosemary Chesson, Head of the Health Services Research Group at Robert Gordon University, described her research into how carers feel they are viewed by health professionals. She explained that carers often feel abandoned at the time of diagnosis even though their lives were affected too. They also felt that they were left to seek out crucial information on their own and a more pro-active approach from service providers would be welcomed.

Professor Chesson also found that there was a lack of support during hospitalisation periods. This is a very stressful time for carers and not respite, as some have suggested. Many carers had not been approached by ward staff for their views. The study indicated that this must change and carers should be more involved in decision making. There is also an issue of understaffed wards, meaning that nurses have less time for carers. It appears that if carers do not seek help, the assumption is that they can cope and it takes a major problem to trigger any real intervention. Some of the health professionals questioned admitted that they do tend to put their own needs first.

Rob Warren, Director of the Edinburgh Young Carers Project and member of the Scottish Young Carers Service Alliance, raised the question of how being a 'key partner' can work for young carers, especially when some are as young as five. He described the findings of two pieces of research carried out in Edinburgh in 2002 and 2004. The studies showed that young carers have distinct needs which differ from those of adult carers. They are especially vulnerable in terms of mental health problems and child protection issues.

Young Carers are not receiving the support they need and, as a result of this, take longer to recover from mental health problems. A survey carried out by the University of Edinburgh in 2002 identified the issues that particularly concern young carers. Some worries were typical of the age group, but there were also significant concerns in relation to caring and the cared for person. Young carers are more likely to suffer from sleeping and eating problems, to self-harm, to have suicidal thoughts and to have contact with the police because of parental drinking. So what can be done to help young carers? Mr Warren described just some of the work his organisation undertakes, including bringing young carers together to share experiences, organising group activities and breaks from caring and other support such as counselling. General awareness of the complexity of the needs of young carers must be raised and investment is also required in local services and in a strong infrastructure to support young carers.

Isobel Allan gave a very moving account of her life and work as a carer of her twenty-four-year-old daughter Susan. Susan requires a very high level of care and this is provided by Isobel and her husband. Isobel described the various ways that being a carer can affect a person's health and well being, including the financial strain and the major stress involved when the cared-for person is admitted to hospital. She was keen to emphasise that what she wanted was not special treatment but the same rights as everyone else, the right to sleep, eat and work and for the same human rights for her daughter. Improvements in disabled toilet facilities and better hospital discharge planning are just some of the things Ms Allan is campaigning for. She saw the current system as one which is power-based and overlooks the uniqueness of individuals. To alleviate the strain of caring, she recommended adequate equipment; accessible and relevant information; training; supporting staff; ongoing investment in the voluntary sector; decreasing bureaucracy and secure financial, emotional and physical support. She added that carers must be involved at every level of the decision-making process, their skills and expertise must be used.

Question and Discussion Session

During this session, delegates shared their experiences of going to their GP as a carer. Some felt that they were too easily told that they suffered from depression rather than being offered the kind of support they needed. Rosemary Chesson made the point that healthcare staff do not have enough contact with carers and often take the attitude that as professionals they know best. Clearly, this is not a helpful attitude.

Session Three: Key Partnerships in Promoting Health

The third session began with a performance by Endeavour Arts entitled 'If only...' which highlighted some of the typical obstacles carers face.

This was followed by a presentation from **Alexis Jay, President of the Association of Directors of Social Work**, on local authority best practice during which, she emphasised health as a very significant dimension of a carer's ability to continue in their role. She described the way in which local authorities can take a direct role by sending out questionnaires to carers to find out what their concerns are.

Multi-agency working, integrated planning and consultation of carers in the early stages are crucial to successful policies. She also recommended setting up strategy groups, which are specific to particular illnesses or conditions. Other beneficial services which local authorities can provide include: delayed discharge from hospital; carers' assessment and support plans; access to training and more flexible short breaks services. These are just some of the ways that intervention can prevent health breakdowns.

Frances Simpson, Centre Manager for the Dundee Princess Royal Trust for Carers, explained what the Dundee GP and Pharmacy Project has achieved. She highlighted the fact that carers visit their GPs much more than the average person and emphasised that primary healthcare workers can play an important role in identifying carers. Various methodologies for identifying carers include working directly with staff on their caseloads and questionnaires being sent out to carers. Other recommendations included having a named member of staff to keep everyone in the practice informed, having a support worker post and asking all staff to generally be aware. Many carers between the ages of 25 and 45 who work, do not seek help. The key messages that have come out of the Dundee project are: partnership, with pharmacies and carers organisation, for example; dedicated staff time; commitment from managers and policy makers and a pro-active approach to information and support.

Dr John Gillies, a member of the Royal College of GPs' Scottish Council, outlined what has been done in his practice in the borders to identify and support carers. He emphasised that GPs are in a key position to identify carers, recognise their health needs and point them in the direction of services and support. In the area covered by his Selkirk practice, Dr Gillies has around 400 carers. Once identified, carers can benefit through access to relevant information, financial help, respite care, meeting other carers and overall the avoidance of crises. The response from carers has been very positive. One carer said "It took away the feeling of being alone with your problems, as others were there to help."

Question and Discussion Session

In the question and answer session delegates asked what is being done about the ignorance of some GPs and also whether GPs should be made more responsible for identifying carers and then referring them to other agencies. Dr Gillies said that the RCGP was promoting the values of general practice and not just the technological side of things. He suggested that GPs should take a holistic approach and added that he did not think GPs should be solely responsible for the referral of carers. Alexis Jay suggested that the NHS has been too inactive on the issue of information sharing and that better frameworks need to be set up.

Session Four: Question Time

David Wiseman, Director of Operations at the Care Commission, began the final session by explaining what his organisation is doing to establish carers as key partners. The Care Commission was established two years ago with the aim of regulating, and therefore helping to improve, the quality of care services. Regulation is based on legislative requirements and the National Care Standards. These are based on three principles:

- keeping people safe
- supporting independence
- promoting dignity and choice

Mr Wiseman emphasised that the Care Commission wants people who use care services and their carers to be empowered, treated equally, supported and able to choose. They have a Public Participation Strategy, which aims to facilitate sharing of information and the involvement of carers in the process of regulation. A key part of this is allowing the board to hear directly from the public. Other ways in which participation is being enabled include; interviews during inspections, sending out questionnaires, focus groups and using lay assessors.

Panel Discussion

The panel comprised:

- Ursula Corker MBE, Carer & Chair of Carers Scotland Committee
- Roseanna Cunningham MSP, Convenor of the Health Committee, the Scottish Parliament
- Ian Gordon, Acting Chief Executive, NHS Scotland & Director for Service Policy and Planning at the Scottish Executive Health Department
- Michael Hirst, Research Fellow at the University of York
- David Wiseman, Director of Operations at the Care Commission

Roseanna Cunningham MSP began the discussion by expressing her concern that, since devolution, much had been said about the issue of carers' health but there is still ambivalence about delivery of concrete results. Ursula Corker added that it is difficult for those outside the central belt to participate because they cannot attend consultations organised by the Executive.

One delegate asked the panel how much training is available at the moment. Ursula Corker explained that Carers Scotland is currently in discussion with City and Guilds in London regarding a training scheme for unpaid carers.

Other delegates expressed concerns that local authorities are not doing enough because of the way that legislation is worded. It is open to interpretation when words such as 'may' or 'could' are used. Roseanna Cunningham explained that this is known as 'enabling' legislation and that if it were more prescriptive it would cause major budgetary problems for local authorities. However, she did add that this must change and local authorities need to spend more in this area. Many delegates agreed that 'informal carers' means 'care on the cheap' to politicians and that carers at the very least deserve basic training. It was also suggested that training would help to improve the status of carers generally. Ian Gordon pointed out that it is being organised at a local level. Roseanna Cunningham described the challenge as providing training that can meet the massive variety of needs of Scotland's carers. Michael Hirst recommended that the Executive should also be thinking of improving the financial security of carers, including the issue of pensions, since it is a major cause of stress.

Next Steps

Keith Makin, the Programme Director of Care 21, concluded the day's speeches with an overview of the project. Care 21 hopes to:

- predict future needs
- seek out best practice
- support change
- help develop new and innovative ways of working

As an organisation, Care 21 aims to be small, non-bureaucratic and fast moving. Its Futures Exercise will look at the needs of unpaid carers over the next ten years, involve as many stakeholders as possible and build a robust evidence base for the next steps on the Carers Strategy. Care 21 will soon launch its own web site, which will contain all documents and an online survey. Final reports will be published in March 2005.

Conclusions

Delegates were in general agreement that the day was valuable and worthwhile. Several commented on the good turnout. The main points to come out of the day can be summarised as follows:

Training

Several delegates suggested that some form of training would be of benefit to carers, who often find themselves thrust into difficult situations with little experience or knowledge of where support and advice is available.

Support

There was some criticism of health professionals, who did not always pay enough attention to carers views and opinions. However, the electronic polling showed that other people had positive experiences with health sector staff. Greater consistency of approach would be helpful, rather than relying on the initiative and common sense of individuals.

Involvement and Consultation

This was by far the most frequently raised topic. There was a real feeling that it was of no use for government to merely pay lip-service to the idea that carers should be involved as 'key partners', there needs to be substantive action to ensure that carers views are sought. And not just sought, but acted upon.

Polling Results

Who are you?

Carer 14%, Scottish Parliament/Executive 9%, Local Authority 20%, NHS 9%, GP 1%, Pharmacist 0%, Voluntary Organisation 31%, Education Provider 3%, Private Sector 3% and Other 9%.

Given the recent legislation and guidance issued by the Scottish Executive, do you feel there is evidence that carers are treated as “Key Partners in the provision of care”?

Yes 27%, No 59% and Don't Know 14%.

Should carers be actively involved in decisions about care arrangements when the person requiring care is discharged from hospital into the community?

Yes 96%, No 3% and Don't Know 1%.

Do you think there is a need for a separate national strategy for young carers?

Yes 90%, No 7% and Don't Know 3%.

Do staff in the NHS take seriously the knowledge which carers have about the condition of the people they care for?

Always 3%, Usually 1%, Sometimes 33%, Rarely 42%, Never 12% and Don't Know 9%.

Do GPs provide carers with the support and information they need?

Always 1%, Usually 2%, Sometimes 42%, Rarely 36%, Never 8% and Don't Know 10%.

Should there be legislation giving carers the right to two weeks free training when they begin caring?

Yes 59%, No 17% and Don't Know 24%.

Should staff likely to be dealing with carers be given cultural training to reduce barriers for ethnic minority carers?

Yes 93%, No 3% and Don't Know 3%.

How well do you think the position of informal carers in Scotland is understood by the Executive?

Not well at all 42%, Reasonably well 51% and Very Well 7%.

In a general election should we expect all political parties to make commitments to carers in their manifestos?

Yes 91%, No 5% and Don't Know 5%.