



Investment

Respite

£135 million

Training

£ 1.5 million

Support services

£ 10 million

Young carers

£ 1 million

Total

£147.5 million

Savings

Unpaid carers

£ 5.3 billion

CARERS HAVE VOTES
... IT'S TIME TO DELIVER

It costs £2,500 a year to give me the support I need

... it could cost £25,000 if you don't

**Scotland's Carers
Manifesto 2007**

www.scotlandscarersmanifesto.com

On behalf of 480,000¹ unpaid carers, Scotland's carer organisations are calling on all political parties to increase investment in carer support, in recognition of the growing contribution carers make to our society.

Scotland is a caring society

- thanks to 480,000 people who care – without pay – for a family member, partner or friend, who may be frail, ill, disabled, or dependent on drugs or alcohol.
- thanks to 115,000 carers who care for over 50 hours a week, and at least 17,000 young people with caring responsibilities.

For years to come, their numbers will grow. People will grow older, live longer, and seek even more family support to live independently.

Scotland needs healthy carers

- because 660,000 carers contribute £5.3 billion worth of care – more than half of the entire budget of Scotland's NHS.
- because it costs Scotland £1 million for every 85 carers forced to give up caring due to ill health.

If just five carers out of every 100 were unable to care, Scotland's public services would be faced with a bill for £280 million.

Scotland must invest in carers

- because only one in 1,000 carers have had their needs assessed.
- because tens of thousands care without breaks and adequate support.

Investment in carers can prevent expensive admissions to hospital and residential care, and improves the quality of life for thousands of people.

Carers have votes – it's time to deliver!

¹ The Census gave a figure of around 480,000 carers in Scotland. However, it is widely accepted that this figure represents an underestimate, particularly in relation to young carers, carers from minority ethnic community and due to the fact that many carers do not recognise themselves as carers but rather as daughters, spouses etc. The most recent Scottish Community Care Statistics estimated that there were more than 660,000 carers in Scotland which is accepted by the Scottish Executive in the recent Care 21: The Future of Unpaid Care in Scotland.

Every carer has a right to good health

Unpaid carers are the pillars of Scotland's community care, with 115,000 caring full time, without pay, for over 50 hours a week. Their numbers are growing year by year.

Lack of support means an increasing number of carers are forced to give up caring every year due to the detrimental effect caring has on their own health. As a result, Scotland pays a high price replacing lost care.

But more importantly, carers pay a high price when their own health becomes the casualty of lack of support.

- 1 in 5 carers suffer from poor health.
- Carers are a third more likely to become permanently sick or disabled than people with no caring responsibilities.
- Half of carers who provide substantial care have suffered a physical injury due to their caring role or have received treatment for anxiety, depression or mental ill health.
- Causes of ill health and injury among carers include:
 - lack of breaks
 - being constantly on call, with disrupted sleep
 - lack of training and assistance with physical care tasks
 - isolation
 - the stress of being on a low income
- It costs Scotland £1 million for every 85 carers who give up caring due to ill health. If just 5 carers out of every 100 were unable to continue caring it would cost more than £280 million.

Time to Deliver:

- NHS Carer Information Strategies must be fully implemented across Scotland by 2009 to prevent today's carers becoming tomorrow's patients.
- From 2007, at least 5,000 carers must receive a carer's assessment each year.

Examples of Good Practice

Hidden Carers GP Initiative - Princess Royal Trust - East Ayrshire

As part of a national initiative by the Princess Royal Trust Carers Centre, the East Ayrshire Carers Centre is working collaboratively with a GP surgery in East Ayrshire to assist with the identification of hidden carers. General Practitioners are being encouraged to write directly to their patient list to raise awareness of the issues which might be confronting carers. It is hoped that this will enable carers to identify themselves and to seek assistance from agencies such as the local carers centre. This process has enabled a large number of carers not previously in receipt of services to contact the carers centre for information, advice and support. Where the carers centre cannot provide the appropriate support, there is an onward referral system. The assistance requested has ranged from benefits advice and help with applications to referrals to other services such as occupational therapy. (Source: Community Care Works: Database of Good Practice)

Finding the Balance: Promoting Positive Health – Carers Resource Guide to Health and Wellbeing

As part of an initiative to promote the health needs of carers, Carers Scotland produced a health resource guide for carers. The guide aims to help carers maintain and promote their own health and provides information on getting support in their caring role. The guide covers a range of topics including eating well, sleeping well, back care, emotional good health, exercise and complementary therapies. Over 5000 copies of the Guide were disseminated with many more copies downloaded at the Carers Scotland website. Since its printing, Carers Scotland has developed further information online including coping with caring and keeping warm and well.

(Source: Carers Scotland)

Every carer must be able to access regular and appropriate breaks from caring

For most carers, breaks from caring are an essential lifeline. They provide a much-needed release from the physical and emotional demands of their caring responsibilities. The benefits of breaks are widely recognised, yet suitable, regular breaks from caring remain out of reach for most carers.

- 39% of carers have not had a break from their caring responsibilities lasting longer than 2 days.
- 84% of carers experience tiredness and stress as a direct result of their caring responsibilities
- 46% experience feelings of loneliness and isolation
- Carers have identified the right to regular breaks from caring and better quality respite options as their top priority. Carers want the Scottish Executive to address these issues to improve the quality of their lives.

Time to Deliver:

- By 2011, carers in greatest need must have a minimum annual entitlement to breaks from caring.
- From 2008, additional investment of £135 million per annum must increase availability and access to high quality short break services.
- National and local Short Break Strategies must be developed and delivered against clearly defined improvement targets. The emphasis of the targets should be to improve the quality, range, flexibility and accessibility of services, and to give carers and service users greater choice and control.

Examples of Good Practice

Lend-A-Hand - Enable Scotland

Abstract Lend-a-Hand in Fife aims to provide respite support to local families who are caring for a child with a learning disability which will enable the child to continue living with their own or a foster family. Children are placed with 'host families' for breaks which can vary from a few hours to up to 2 weeks at a time, thereby giving parents and child respite from each other. An open referral system is available to parents, although professionals also refer children. Contact is made within a few days by the scheme co-ordinator and, following discussion with parents, those who apply are registered on a waiting list. Host families are recruited locally and attend preparation and training groups and children's get-togethers along with families on the waiting list. Currently there are 61 host families offering a service to children, mainly on a one-to-one basis. Children visit their host family for up to 42 days per year.

Crossroads Caring for Carers, Harris

This scheme offers relief and support to carers by providing a care attendant in client homes, enabling carers to take a break from caring. The users may be carers of any client group. The scheme covers mainland Harris and its offshore island of Scalpay. Clients are referred by a care professional and the scheme coordinator. Needs are assessed and a suitable care attendant is matched to the client. The scheme aims to be flexible: five hours are allocated per client per week but this can be increased to nine hours, and the coordinator has the discretion to provide whatever short-term cover is necessary in times of crisis. At a carers' conference in Stornoway, a client making a presentation called the scheme "a shining example of support for carers".

The Oxfangs Pentland Carers' Project - Edinburgh

The Project provides a range of services to carers and those for whom they care. The befriending service matches volunteer befrienders with a carer or person being cared for. The befriender visits the person in their own home to plan stimulating activities in the community using mainstream services. The respite service enables local carers to have a break from their caring duties by providing a suitable, experienced paid worker to look after the person with specific needs in their own home. The service is available for service users with a range of specific needs including dementia, children and adults with physical and learning disabilities and adults with mental health problems. A minimum respite break is two hours and a maximum 4 hours, the service is free to those under 16 with a small charge for those over 16.

(Source: Community Care Works: Database of Good Practice)

Every carer must have access to appropriate support

Voluntary sector carer organisations are the main providers of information, advice, training, advocacy, emotional and practical support, and help with financial and legal matters.

As more carers are identified by NHS and social services they will be referred to carer organisations for specialist support. Carer organisations need further investment to consolidate and develop their capacity to support carers.

- 60% of carers who were informed of their statutory right to a carer assessment were informed by their local carer organisation.
- 75% of carers named a carer organisation as their source of support. Just 9% and 4% named their local social work department or health service.
- 19% of carers say if they had received more support as a carer, it would have prevented the person they care for being (re)admitted to hospital.

Time to Deliver:

- By 2008, an additional £10 million must be invested in carer organisations to consolidate Scotland's carer support infrastructure. Carer organisations must be equipped to deal with the increasing numbers of carers referred to their services.
- Carer organisations must be recognised as vital partners and their services safeguarded through long-term funding arrangements.

Examples of Good Practice

East Ayrshire Information and Advice for Carers and Families

East Ayrshire Princess Royal Trust for Carers set up the Home from Hospital initiative providing support and advice for the carer during and after a hospital stay. The initiative ensures that carers of people leaving hospital are aware of the services available, and have immediate access to their local Carers Centre and other support systems. The initiative has included the production of ward discharge packs for carers and on-site availability of carers centre staff in acute hospital settings. The in hospital worker, based at Crosshouse hospital visits the wards once a week, identifies those patients who may be in need of care or support following discharge, and leaves a card with them. Completed cards are deposited in a bag at the nursing station in the ward and collected by the hospital worker at the end of every week. Cards are collated at the East Ayrshire Carers Centre and distributed to other centres in Ayrshire as appropriate. Arrangements are made for people to receive a home visit from a member of staff from the centre, or they are invited to attend the centre. At this visit information is provided on benefits, aids and adaptations and the availability of various activities put on by the Carers Centre. If the carer is a first time carer the issue of respite care is explored.

Carer's Resource Book, Princess Royal Trust Carers Centre, Aberdeen

The Carer's Resource Book is a comprehensive resource which enables carers to find out about services which may be of help to them. The book is responding to the needs of carers for information about statutory, voluntary or independent services. Carers wanted a convenient source of information that was accessible without having to make numerous contacts to disparate organisations. The publication is a resource for carers of all ages who support and look after or help a relative, friend or neighbour. The book covers: services in the home; housing options and adoptions; respite; residential and nursing home care; assistance in getting out and about; money matters; bereavement support and local services.

Princess Royal Trust Borders Carers Centre

The Centre provides advice, information and support for carers and assists carers to have a voice in the planning and provision of community care services in the Borders. A survey of carer needs demonstrated the need for practical advice, information and informal support for carers in the widely scattered rural area. The Centre provides one-to-one support through the drop-in, home visits and mutual support through a network of carers groups across the Borders. The carer support groups include one for people who care for someone with a mental health problem. Information packs for carers and a Carers Emergency Card are distributed by community health staff and at Borders General Hospital as part of its discharge procedure.

(Source: Community Care Works: Database of Good Practice)

Every carer must have access to carer training to support them in their caring role

Unpaid carers carry out the same tasks as paid care staff, often including personal and medical care. They therefore deserve the same information and training to ensure they are equipped to deal with their caring role.

- 2 out of every 3 carers who provide medical care have not received any training or guidance on medication, dressings or injections.
- Only 3% of carers have been taught how to lift properly, yet our health-care workforce are trained in moving and handling patients safely.
- Research shows that carers training can drastically improve their wellbeing and access to support. Training strengthens carers' ability to manage their caring situation, and reduces the cost of patient care.

Time to Deliver:

- £1.5 million must be invested each year to develop and deliver comprehensive Expert Carer training programmes.
- All carers must have access to appropriate training, delivered free of charge, tailored to meet their caring situation.
- Health Boards and Local Authorities must promote training opportunities for carers and will invest in the development and local delivery of Expert Carer training.

Examples of Good Practice

Alzheimers Scotland - Carer Support Service

The Moray Carer Support Service provided by Alzheimers Scotland provides carers, families and friends of people with dementia advice, information and support on a one to one or group basis. The service provides skills, training and education. Topics such as: what is dementia, handling stress, coping with challenging behaviour and welfare benefits.

Training for Carers - North and South Lanarkshire

The Carer Training programme is a joint initiative run by the Princess Royal Trust for Carers, Lanarkshire Carers Centre and funded by North Lanarkshire Council and South Lanarkshire Council. The initiative aims to provide quality training for carers to support them in carrying out their crucial role. It promotes carers as key partners in the delivery of community care and therefore it assumes carers have the right to expect the same access to training and personal development as paid staff. The initiative responds directly to an expressed need for training by carers. The same programme, e.g. on dementia is repeated in four separate locations to enable easier access for the maximum number of carers. The topics covered by the courses include epilepsy awareness, first aid, challenging behaviour, sexual awareness/learning disabilities. The training programme is organised to overcome many of the barriers that carers can face. For example travel expenses are paid as carers are often on a low income; a 'carer training day' is delivered between the hours of 10.30am and 2.30pm as carers cannot always be available in the early mornings and often have to be home early for their cared for arriving home from school or day activity; and funds are provided for respite care to enable the carer to attend.

(Source: Community Care Works: Database of Good Practice)

'Expert Carer' training programme

300 carers benefit every year from 25 'expert carer' training courses run by PRTC VOCAL Carer Centre in Edinburgh in partnership with NHS and social care professionals and local carer groups. This 'expert carer' training has a strong prevention focus, targeting carers early in their caring role and aiming predominantly at carers of people with long-term conditions and intensifying caring responsibilities over time (Heart disease, stroke, Parkinson's, COPD, mental health, learning disability, parent carers, etc). Courses cover training on illness or conditions, treatment, medication, access to community care and NHS support, person-centred care planning, financial support, carers' rights and legislation, and specialist support to deal with the emotional impact of caring. Average courses run over 6-8 weekly three-hour sessions.

The programme has been running since 2000, and evolved through systematic pre- and post-course carer evaluation. The programme is funded by the Big Lottery Fund with grant support from NHS Lothian, City of Edinburgh Council and other trust funds.

(Source: VOCAL Carers Centre)

Every child and young person with caring responsibilities deserves the right to be a child first

There are at least 17,000 young carers in Scotland, with less than three thousand currently being supported by the already stretched young carer support projects.

- As many as half miss some schooling and a quarter leave with no qualifications.
- 4 out of 5 young carers will be bullied because of their circumstances.
- A third of young carers self-harm due to stress and over half experience sleep problems. As one young carer put it, "I totally lost my childhood"
- All services who work with children and young people must work together to ensure that young carers rights under the United Nations Convention on the Rights of the Child are preserved.

Time to deliver:

- A minimum additional £1 million each year must be invested to strengthen the capacity of dedicated services. This will provide support for an additional 700 young carers.
- The Scottish Executive must provide a framework for all schools, health and social services to identify young carers.
- The Executive must ensure young carers receive effective support provided by an appropriately skilled and competent workforce.

Examples of Good Practice

Young Carers Project, Dundee User Group

Abstract Youth Care is a youth club for 12 to 18 year old carers in the Dundee area whose lives are affected in some way by caring for a person of any age who has a disability, is affected by substance misuse, is affected by HIV/AIDS or has a mental illness. Youth Care is a partnership of organisations, co-ordinated by the Princess Royal Trust, which includes: Barnardos, Youthlink, the social work department, education department and health visiting service. The purpose of the initiative is to address the needs of young people who may be excluded from traditional support networks of family, school, work and community due to carrying caring responsibilities considered to be exceptional for young people of their age. The project employs two part time workers who can give information and support young people to access further help as well as assisting young carers to put together a programme of fun events. Youth Care Dundee meetings are held weekly and on average 12 young carers attend. Transport to meetings and respite can be arranged to facilitate attendance.

West Lothian Young Carers Partnership

This initiative is part of the Carers of West Lothian project and is able to support up to 20 young carers at one time through group and individual work. Peer support groups, summer programmes and residential trips are also provided. Individual support is offered to young carers with particular complex needs. The project has been successful in supporting and raising awareness of young carers issues, and a major achievement was the launch of the West Lothian Young Carers website designed by young carers (www.wl-yc.com). The site includes links to other sites of interest, details of services provided by the partnership and information of interest to young carers generally.

(Source: Community Care Works: Database of Good Practice)

Every carer must have the right to live free of poverty with opportunities to work and take part in lifelong learning and leisure

Many carers are disadvantaged as a consequence of caring. Carers' income is less than that of non-carers, many have left work to care and frequently cannot access opportunities to develop their potential and live a fulfilling life outside of caring.

- 1 in 3 carers are or have been in debt
- 1 in 5 carers cut back on food. 1 in 3 carers have difficulty paying utility bills.
- 58% of carers with significant caring responsibilities have left work to care. 8 in 10 carers feel it would be difficult to return to work citing lack of confidence (33%), lack of skills (35%) and lack of experience of new technology (38%).
- 4 out of 10 carers face financial difficulties due the level of charging for services
- One third of carers believe caring has had an adverse effect on their relationships with friends, social life or leisure activities

Time to deliver:

- The Scottish Executive, in partnership with their colleagues at Westminster, must call for a full review of carers' benefits and financial support including: an increase in the level of Carers Allowance and the carer premium; the introduction of an entitlement for older carers to receive Carers Allowance alongside their state pension; and the establishment of a carers' element to Working Tax Credit to support carers to combine work and care.
- The Scottish Executive must issue guidance to ensure that carers will not be charged for services to support them in their caring role, including breaks from caring.
- The Scottish Executive must extend concessionary travel for carers (which is not dependant on travelling with the person they care for) to enable them to access leisure, education and social activities.
- The Scottish Executive must issue practice guidance on carers assessments to ensure that these will identify services to support carers' wishes to work and take part in training, leisure and education
- Carers will have access to flexible and imaginative lifelong learning opportunities. Funding bodies, education providers and national organisations such as Learn Direct Scotland will work in partnership with local authorities, the NHS, local and national care organisations to develop and deliver these opportunities.

Examples of Good Practice

CA(i)RE Project, Edinburgh

The Project was formed as the result of a joint initiative of the Eric Liddell Centre, VOCAL, Lothian Health Board, the Community Education Department, the Social Work Department, the Pastoral Foundation and Carers. The above formed a working group and devised a pilot project to ascertain the demand for courses which address the educational, recreational and therapeutic needs of carers as opposed to the needs (direct or indirect) of those for whom they care. CA(i)RE aims to provide opportunities for carers in South Edinburgh to acquire or enhance their skills of an educational, recreational or therapeutic nature, necessary to undertake or sustain a caring role and to prevent a breakdown in physical or emotional health. The project responds to carers' identified needs and provides an ongoing programme of educational, recreational and therapeutic courses, many tutored by carers themselves. The project has provided variety of courses for participants including reflexology, basic literacy skills, communication and educational guidance. (Source: Community Care Works: Database of Good Practice)

Learning for Living

Learning for Living is an online learning programme for carers developed by Carers Scotland in partnership with City & Guilds. It builds on the skills that carers and former carers have developed in their caring roles. It also helps to build confidence and develop computer skills, and could pave the way for further study or a return to a paid job. Learning for Living is a combination of an on-line learning programme for carers and a qualification. There are two parts: the qualification known as the 'Certificate in Personal Development & Learning for Unpaid Carers' and the learning resource known as Learning for Living. This is the first qualification and learning resource designed specifically for carers by carers. The certificate is supported by Learning for Living. Learners who do not want to take the qualification can opt for doing just the resource. (Source: Carers Scotland)

Carers' Experiences

✓ Every carer has the right to good health

Betty and David's Story²

Betty is 59 and has been caring for her husband for the past 11 years. Her husband, has had a stroke and heart attack and suffers from angina, diabetes and emphysema and has memory loss and confusion. Betty has her own health problems including fibromyalgia and cervical spondylosis. She is needed day and night – to provide physical help such as lifting and help to get out of bed and other tasks such as helping with bathing, foot care and checking to make sure that David does not have any sores on his legs. She also needs to provide emotional support as David's confidence has been badly affected by his illnesses and forgetfulness and, to remind him to take his medication and test his blood regularly. She feels that she cannot leave David alone without arranging for someone else to be there and says *"I am on call all the time"*. Physically, Betty often suffers from pain and muscle spasms linked to her physical problems but aggravated by her caring role. These spasms are made worse by often being tense and stressed. She also feels her emotional wellbeing is also affected; often feeling tired, stressed and depressed. She says; *"Sometimes I wish that nobody wanted me."*

Her GP knows she is a carer and, she describes him as *"an invaluable source of help"*. He has helped her with finding the right medication to help manage her pain and he provides information and advice on David's medication and health. Most importantly, he is a listening ear. Often when she visits her GP *"he just lets me talk"*. Her GP also referred her on to get mobility rails fitted around the house and rails to help David get in and out of bed with less assistance; reducing the amount of lifting Betty has to do. The practice physiotherapist, who Betty and David both attend, is also a great listener and gives Betty information on David's treatment as he cannot remember what he is told when he visits. And, the local district nurse has helped by ensuring that incontinence aids are delivered regularly. Betty cannot praise the practice highly enough.

The social work department have also helped, although she had to wait over a year for a carer's assessment. As David refuses to accept any personal care services, they have helped provide other services including: a shower and bath seat, a chair that it is easier for David to get out of and an ironing service to help Betty manage.

To help her own health and wellbeing, Betty attends the guild once a week and goes swimming after it. She has to arrange for someone else to be available to care for David but describes it as *"my one time off and out of the house each week"*. It gives her the opportunity to meet up with her friends and spend some time thinking about other things. She has been able to try some alternative therapies at "taster sessions" run at events by local sports centres and voluntary organisations – and enjoyed foot massage and head massage. She has also tried out tai chi – *"quite relaxing"* and has visited a chiropractor – *"very useful, helped me get walking properly again"*.

✓ Every carer must be able to access regular and appropriate breaks from caring

Guy and Gail's story³

"I'd been waiting for respite for over a year and the arrangement with the proposed link family was breaking down. I already lived life on a knife-edge, but this was the final straw, the breaking point. In tears on the phone I told social services that I couldn't cope any more. I was exhausted and my marriage and family was falling apart. If I didn't get respite they would have to take Guy away. Within a week I had overnight respite for Guy."

For the last nine years we have got four or five nights' respite per month at a children's centre near to our home. This means we can have a weekend where Guy goes to the respite centre from school on a Friday and comes back on a Sunday, or on a Monday evening after school.

Guy has really benefited from the short breaks. It is like a second home. He knows the routine and the staff so well that it really is a substitute family. The breaks we get are regular and good quality. The respite centre does activities with Guy that are appropriate to his developmental level and that we don't have the time and energy to do with him when he is at home. The breaks mean Guy is used to being away from home, and that's good because I do want Guy to be able to move on eventually. Just as his sisters go to sleepovers with their friends, time at respite is Guy's chance to do that. He can socialise with his friends and gets one to one attention. The breaks are a lifeline, but they only work because they are regular and reliable and a good length of time."

² Source: Carers Scotland

³ Source: Breaking Point: Families Still Need a Break, Mencap (2006)

Carers' Experiences

Jodie and Stephanie's story⁴

"Because Jodie has complex health needs it is a battle just to be able to live day to day in her own community. I have had to fight to get things for Jodie just so that we can carry on with daily life. I don't know why health and social services have to wait until you're in crisis before they step in to help. I now get some home-based support, basically an extra pair of hands to help me care for Jodie. It isn't really a break, because I still need to be here doing everything for Jodie, but it just means that I have a bit of support to do it. But Jodie also goes to a short break centre for a weekend every six to eight weeks. This works pretty well but it's still not enough and my real worry is what happens in an emergency. I had a carer's assessment and was told that I needed extra help and would be given direct payments and support from a sitting service. However, because of the cuts in my area, these extra services that I need have been put on hold. I have been told that I have a need, but no one is going to provide anything for me.

The short break centre has one emergency bed, but it is supposed to cover the whole county. This means that only one family at a time can have an emergency. My emergency came in May this year. I needed to go into hospital, but the bed in the respite centre was already filled. It meant that my appointment was cancelled. I really don't need the extra worry and stress. I have had to fight every step of the way to get a short break and I know that some families just aren't able to do that. I really don't know if there's any fight left in me any more. What's important is that every family gets what's right for them. For me, that's having consistent and flexible support in caring for Jodie."

✓ **Every carer must have access to appropriate support**

Woman caring for her husband now in residential care, North Ayrshire⁵

"Without the carer's group and without that support, I would have found it very difficult. I wouldn't say that I used the social services any more than was necessary. This was more support to me, I have to say, than social services, until the stage where I am now where he has to go into full time care and they have been very supportive; but before that, they didn't offer me a support group like this where you could go and talk to people and things like that. This gives me time to talk about it and listen to other people.

Woman caring for her daughter, North Ayrshire⁶

"Because you can get out of the house, you can meet other people and we don't tend to dwell on our problems but there is somebody there that will understand if you have a problem and will now where you are coming from. We cheer each other up. A therapist usually comes so we'll get a therapy session which is very relaxing, aromatherapy or a massage so that it gives you a big boost."

✓ **Every carer must have access to carer training to support them in their caring role**

Anne and Duncan's story⁷

Duncan is 48, he suffers from severe autism and mental health problems. His mother Anne is 82 and has been Duncan's main carer since he was born. Following a brief spell in hospital, Anne became increasingly aware of her own mortality and the fact that she will not be able to provide care for him for ever. This concern prompted her to attend a training course for carers.

Through the course Anne learnt about how to effectively leave money in her will and went on to make changes and establish a trust. She also learnt more about community care law and the support available from health and social care agencies. This prompted her to make contact with the local authority who now look into enhanced support for her and Duncan.

Anne also found out about a support group for parents in her situation and now regularly attends. She is still concerned about the future, but feels that as a result of the training course, she and Duncan are much better linked in to support services, which has given Anne some peace of mind.

⁴ Source: Breaking Point: Families Still Need a Break, Mencap (2006)

⁵ Source: Care 21: the future of unpaid care in Scotland, 2006

⁶ Source: Care 21: the future of unpaid care in Scotland, 2006

⁷ Source: VOCAL Carers Centre, Edinburgh

Carers' Experiences

Jane and Stuart's story⁸

Stuart is 16 and has global learning delay. His mother Jane attended a course for parents of children with additional needs. She had heard about the course through a friend who had attended a similar one previously.

Through talking to other parents on the course she found out about a local fun day for families affected by disability, and sports groups for children with mobility problems, gained a cinema exhibitors card and a bus pass for her son. Jane gained a much better understanding of support services and how to access them.

Following presentations by a pharmacist and dietician, she contacted her GP to discuss changes to her son's diet and medication regime. Realising the importance of her own health, Jane registered for a course on "how to look after yourself" while caring and attended a stress management event.

Betty's story⁹

Betty's husband was diagnosed with dementia a year ago, but she had been caring for him for a fair while already. A friend recommended to her to attend a carer training course at VOCAL, med specifically at carers of people with dementia. Through the presentations from expert speakers Betty discovered that she could apply for attendance allowance on her husband's behalf, and that they could also claim a 25% discount on their council tax bill.

From medical professionals and other carers she learnt how to manage some of her husband's difficult behaviour and now feels better able to cope. Through another carer in the group she learnt of a lunch club, which her husband now attends.

Betty feels very positive about her experience on the course and speaks about how she feels less isolated knowing she can always come back to VOCAL for support and advice. Since the course Betty has accessed other forms of support she had heard about on the course – relaxation events art classes specifically for carers and a number of groupwork events focusing on the emotional challenges of caring.

✓ Every child and young person with caring responsibilities deserves the right to be a child first

BME man who has cared for his mother since he was a teenager, Edinburgh¹⁰

"I missed school at times. I felt lost and on my own. When the kids I went to school with talked about cartoons, I had no idea what they talked about. I felt nobody understood me. I didn't even feel comfortable talking to the doctors."

15 year old girl caring for mother with arthritis, Irvine¹¹

"It sort of hard because I have to keep missing school to take care of her but the teachers are all very helpful and send work home for me. I've missed it every day this week because my Mum, she's been stuck in her bed. I had to take her to the toilet and help her in her chair and that and help her about the house and stuff"

✓ Every carer must have the right to live free from poverty with opportunities to work and take part in lifelong learning and leisure

Jane's story¹²

Jane, a full-time carer for 8 years from Katrine, felt a real achievement from taking part in Learning for Living: *"It's given me confidence to go into more education in the future. The course helped me feel like I belong to a group, the interaction I had with other carers both physically in seminars and online was empowering, we could share our problems. Plus, I was finally able to get over my IT fear!"*

⁸ Source: VOCAL Carers Centre, Edinburgh

⁹ Source: VOCAL Carers Centre, Edinburgh

¹⁰ Source: Care 21: the future of unpaid care in Scotland, 2006

¹¹ Source: Care 21: the future of unpaid care in Scotland, 2006

¹² Source: Carers Scotland, Learning for Living awards

Carers' Experiences

Sarah's Story¹³

Sarah, a carer for 5 years, studied Learning for Living at The Glasgow College of Nautical Science (GCNS). Jill found the course to be a real confidence builder: *"It opens your eyes to understanding yourself better... working out your personal strengths and weaknesses and gives you skills that would help for CV building in the future! It felt great. This is my first qualification since my English 'O' level, gave me great satisfaction helped me learn about myself and my inner strengths. It improved my computer skills enormously."*

Sole carer of adult son with autism, Edinburgh¹⁴

"I have no pension, I've never had any money to put into a pension. If anything was to happen to my son, I am left with nothing"

Carer in her 60s, Inverness¹⁵

"You know, the government is always talking about caring for carers. Well, they are not doing a wonderful job. I have up my job to look after my husband and I did get Carers Allowance. Then I became 60 and got my pension. This is a known. I should look after my husband. It's my duty. If you can't look after your husband, who can you look after? But for my age group, our pension was not good, because we got poor advice in the 70s. My pension is something like £37 or something to that effect. This is what I get. They stopped my Carers Allowance. I am getting older. I have quite bad osteoporosis of my own. I am not trying to moan about it. Life is getting harder for me to run the house, look after my husband and grandchildren. My personal money is limited. That's my lot. I try not to be a burden to social services. I don't even take all my respite".

Carer of a son with mental health problems, Easter Ross¹⁶

"I am thousand's of pounds in debt. There was nothing in the services. They never mentioned any support. I am not getting any help other than what I pay for. They (the GPs) just walked away".

¹³ Source: Carers Scotland, Learning for Living awards

¹⁴ Source: Care 21: the future of unpaid care in Scotland, 2006

¹⁵ Source: Care 21: the future of unpaid care in Scotland, 2006

¹⁶ Source: Care 21: the future of unpaid care in Scotland, 2006

Facts and Figures

- 1 in 8 of the population are carers
- There are 480,000 carers in Scotland
- There are more than 16,000 young carers in Scotland, with over 1000 of these young people providing 50 hours or more of care each week.
- Every year 178,000 people become carers Carers save the Scottish economy more than £5 billion – more than half of the cost of providing NHS services in Scotland.
- Carers Allowance, the main carers' benefit is worth just £46.95 for a minimum of 35 hours - £1.34 per hour
- 115,000 people provide over 50 hours of care per week
- 3 in 5 of us will become carers at some point in our lives.
- 63% of carers are women; 37% are men
- By 2037 the number of carers in Scotland will have increased to around 1 million.
- 6 out of 10 carers providing substantial care report that worry about their finances is affecting their health.

Older Carers

- Carers lose out on £70 million of carers benefits. Older carers particularly hard hit with estimates showing that in just the Carers Allowance alone £10 million is going unclaimed.
- One in 10 older carers has cut back on food to make ends meet
- Nearly 4 in 5 have cut back on essentials and activities.
- Leaving work early to care mean that many older carers have difficulty in saving for a pension – meaning the financial impact of caring lasts long after their caring role has ended.

Working carers

- Over 250,000 people juggle caring with holding down a job
- Of those caring 50 hours or more each week, 58% have given up their job to care.
- 1 in 5 of all carers have given up work to care
- 1 in 3 carers would return to work if the right alternative care was available
- 70% of carers say their earning have been affected by caring by an average loss of £9500 each year (1996 figures)
- Leaving work early to care mean that many older carers have difficulty in saving for a pension – meaning the financial impact of caring lasts long after their caring role has ended.
- 80% of carers are of working age.
- The peak age for caring is between 45 and 64. Carers are therefore amongst the most skilled and experienced employees in organisations.
- There is a clear need to support carers in employment or who wish to return to employment by providing flexible alternative care solutions and developing carer friendly working practices.

Health of Carers

- A recent survey found that 79% of carers felt that caring had made their health worse. Carers reported that they experienced stress and worry (91%), depression (58%) and backache (50%) with 73% saying that their health problems affected their ability to care and 59% believing that their health problems affected the person they care for.
- Nearly 70 per cent of carers could have benefited from practical support, such as equipment aids, home adaptations or support from care assistants. Having this would have made a real difference to their health as well as their quality of life - reducing stress and improving their emotional wellbeing

This manifesto has been produced by the national carer organisations in Scotland:

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Carers give so much to society yet as a consequence of caring, they experience poverty, ill health and discrimination. Carers Scotland is part of Carers UK, an organisation of carers fighting to end this injustice and we will not stop until people recognise the true value of carers' contribution to society and they get the practical, financial and emotional support they need. Carers Scotland seeks to improve carers' lives by: providing information, advice and training opportunities to carers and workers; campaigning and lobbying throughout Scotland and at UK government level; developing policy and good practice; and promoting and supporting carer involvement in the design, development and delivery of services. Our CarersLine (0808 808 7777) provides information and advice to around 20,000 carers each year. In one week, we helped carers claim £30,000

The Coalition of Carers in Scotland is a network of over 80 local carer organisations seeking to provide support and collective strength to local carer-led groups. The Coalition aims to: provide networking, information and mutual support for carer-led organisations in Scotland; to bring carers and workers together to explore issues, analyse developments and identify key issues affecting carers in Scotland; to develop a collective response to key issues enabling members of the Coalition to bring their concerns to the attention of interested parties at local, regional and national level.

There are 48 Crossroads schemes throughout Scotland - providing over one million hours of practical support for Carers each year. Crossroads schemes are governed by local volunteers who employ dedicated care staff to provide high quality care in the family home. Crossroads Caring Scotland is the national organisation, which supports the ongoing development of the movement - ensuring that local services are equipped to meet the exacting standards of statutory regulation and carers themselves. Crossroads Caring Scotland also manages the Carers Information and Support Line, which exists to help carers access local services.

The Trust is the largest provider of carers support services in the UK, through its network of 129 independently managed carers centres and interactive websites. The Trust currently provides quality information, advice and support services to 290,000 carers including just over 15,000 young carers. In addition, the Trust also acts independently in the interests of carers through research, development and consultation, influence at national, regional and local policy; partnerships with other national organisations; information through our interactive websites, providing advice and access to support groups.

The Scottish Young Carers Services Alliance represents young carers projects throughout Scotland in promoting and supporting the development and implementation of policy and practices to ensure that young carers are recognised as children and young people first and given the support they need to have a much more normal childhood. There are 26 carers centres with young carers projects attached to them and there are dozens of other young carers projects and clubs in Scotland run by organisations such as Crossroads, NCH and MS Scotland.

Shared Care Scotland promotes and supports the development of short breaks (respite care) throughout Scotland, focusing on ensuring that those requiring short breaks, their carers and their families (wherever they live in Scotland) are offered real choice in terms of what, where and how the services they require are provided. Shared Care Scotland also works to support the further development of "alternative short breaks" throughout Scotland, often referred to as natural breaks without boundaries or community based respite

For more information on the national carer organisation's Time to Deliver campaign, printed summary copies of this Manifesto or details of how you can get involved, contact Fiona Collie on T: 0141 221 9141, E: campaign@scotlandscarersmanifesto.com or visit www.scotlandscarersmanifesto.com