



# Good Practice Carers and Young Carers Stories

Caring Together and  
Getting it Right for  
Young Carers

The Carers and Young  
Carers Strategy for  
Scotland 2010 -2015

26 July 2010





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## Introduction

This compendium of good practice and carers and young carers stories accompanies *Caring Together* and *Getting it Right for Young Carers*. It is available online only.

Earlier this year the Scottish Government invited local authorities, Health Boards, the Third Sector and other organisations to submit examples of good practice about support for carers and young carers. We also invited personal ‘stories’ from carers and young carers. We received so many good practice examples and ‘stories’ that we could not include them all within the strategy, although we have referred in the strategy to good practice and have included short quotes from carers and young carers. The Scottish Government and the Convention of Scottish Local Authorities (COSLA) have therefore produced this compendium.

We are very grateful for all good practice submitted which shows the wide range of support being provided across Scotland. All information was accurate at the time it was received, which was a few months ago. We have edited some of the examples (primarily to shorten them) but we have not radically altered the information submitted to us. Contact details, where available, for the good practice examples are provided in Annex A. There will be other examples of good practice not sent to us.

There is an Action Point in *Caring Together* and in *Getting it Right for Young Carers* as follows:

**Over the next 5 years, councils and Health Boards, with partners, will take account of good practice promoted in local authority and Health Board areas. They will consider how the good practice can be transferred, if appropriate, and/or will consider whether or how existing services and supports can be reconfigured to achieve the best outcomes for carers and for those they care for. As a first step, councils and Health Boards, with partners, will consider the good practice contained in the publication accompanying this strategy.**

The Scottish Government, with COSLA, will consider how best to monitor implementation of this Action Point.

We thank the carers and young carers who provided their personal ‘stories’ which demonstrate both the positive support they received and some of the challenges and difficulties. We have not edited the stories which were also received several months ago. They may not, therefore, reflect the current caring situation but they show the nature of the caring at the time.

## PART ONE: GOOD PRACTICE GUIDE

### 1. Aberdeenshire Council

**a) Carer Involvement:** This is not a service but work which was undertaken following consultation with unpaid carers. Aberdeenshire Council hosted three events to recognise the immense amount of commitment that carers give and work undertaken, in looking after family members. Approximately 200 carers attended the events which were hosted by the Provost and attended by the Director of Housing and Social Work, Senior Council Officers and elected Members. The aims of the event were to give carers some time out, and provide an opportunity to speak to elected members and senior council officers on issues that are important to them. There was also consultation with carers on specific areas that the council is planning on service developments, namely carer assessment and short breaks/respite care.

Aberdeenshire Council is aware of the vital role that carers play in supporting and caring for family members. A report was submitted to Housing and Social Work Committee highlighting the expected increase in the number of carers over the next few years, the vital role that they play and identifying some of the developments that are happening through the social work service to support carers. Aberdeenshire Council asked carers how they would like to be recognised and took forward their suggestions for local, informal events with information available, along with complementary therapies.

Consulting with carers has helped Aberdeenshire Council to improve and develop services around short breaks/respite care and carer assessment. It has also raised the profile of carers with elected Members and shown that the local authority has a commitment to listening to, and working with, carers to improve current services and development of new services.

*“All in all, it was a great evening full of good company, camaraderie, information and opportunities for feedback. It was also a chance to take a small break from my caring responsibilities on a practical level, even though I was constantly thinking about them. It’s nice to be thanked for what is an extremely difficult ‘job’ and to be provided with a forum to provide feedback from carers whose voices are so often unheard as they struggle with the difficulties of their charges daily lives.”*

*“Getting a night out away from being a carer is so good. I appreciate this but we should be recognised more for what we do.”*

*“The company and having the opportunity to speak to Councillors and staff in an informal manner – A good idea.”*

*“Meeting other carers was good. Thank you for recognising carers and giving us a treat – it felt super.”*

**b) Rainbow Rogues:** A support toddler group which provides for families with very young children who have a disability or additional support needs. The children and their siblings are provided with quality play provision and first steps to inclusion while

the parents have the opportunity for some time out with a community worker and other parents who may be facing similar issues. Parents can participate in a programme of adult learning or simply use the time to relax and have some respite from often very demanding 24 hour care.

## **2. Alzheimer Scotland**

**a) Moving on Together (Dumfries and Galloway):** Alzheimer Scotland's Moving on Together project enables carers, who may have become isolated during their caring role, to engage in social activity in the company of people who understand dementia and have had a similar experience. Alzheimer Scotland promotes supportive relationships and friendships within the group, providing opportunities for carers to arrange to meet privately with a dementia worker should they have worries, concerns or difficulties coping with particular aspects of their situation.

Both over the short and longer term, the group provides carers with access to support, which enables them to cope and move forward. Carers remain within the group for as long as it suits them.

Alzheimer Scotland works in partnership with social services, community mental health teams, GPs, and other Third Sector groups who may make referrals, but are not involved in the running of the groups.

***"I have had the very best attention during and after my husband's illness and after he died. I cannot say enough about the carer liaison worker, she helped me so much by listening and talking to me over a cup of coffee or tea. She also encouraged me to come to the Alzheimer's meetings which I enjoy very much and I have made good friends through it as we all have something in common to talk about."***

***"The carer liaison worker should work full-time and take no holidays!"***

***"The carer liaison worker has been a wonderful support above and beyond the call of duty! Can she be cloned?"***

***"I would like to say how lucky we are here in Dumfries and Galloway to have the help we get."***

**b) Dementia Carers Support Group (West Dunbartonshire):** Alzheimer Scotland's carers support group provides carers with a 'one-stop and shop' to access information and support with their caring role. Carers can meet with other carers in a safe, comfortable environment and have regular access to a range of professionals who work with people who have dementia and their carers. In addition the centre offers a range of other services which the carer can access, for example, short break service for carers along with activities for carers, including therapies.

The service is delivered once every month in Clydebank Carers Centre. Carers can, if they wish, bring along the person that they care for as a range of stimulating activities is provided for the person with dementia by a support worker and a volunteer from Alzheimer Scotland.

Alzheimer Scotland works in partnership with Carers of West Dunbartonshire, health workers from the Older Adults Team based at the Glenkirk Centre in Drumchapel, and social work staff from the Community Older People's Team in Hardgate.

*"It makes me feel relaxed to speak to others in the same position."*

*"The old saying 'a problem shared is a problem halved.'"*

*"It's good to meet other carers and learn from them."*

*"I found the people so understanding of what I was going through. I was not alone and my feelings of guilt are not unusual. There was a bond with the people."*

*"Time to ask questions, discuss with others in a similar situation, time to relax a little."*

**c) Home Support (Motherwell):** Alzheimer Scotland seeks to enhance and maintain the social skills of the person with dementia by encouraging everyday skills and hobbies. The service is about doing things with the person and not for them, with the support of family and friends. The time spent with the service users then allows the carer **regular respite** and time to look after their own needs.

The person's carer needed time away as the cared-for person's needs were growing and putting additional demands on the carers who had their own health problems. The service had undertaken trial days at a care home but they were unsuccessful and not conducive to the age of the service user. Also, the fall-out after the trial days caused more stress for the carer and added to the need for appropriate respite.

Discussions took place with the carer about the daily routine of the service user. Consideration was given to looking at the regular support worker providing weekend overnights. Two more workers were recruited for the day time support. This was planned over a week with introduction visits to the person with dementia and carer at their home. The carer provided a written daily routine, as well as contact details of other family, and medication details.

### **3. British Telecom**

Within British Telecom there is a culture of flexibility and support for carers. Approximately 15,000 employees out of a workforce of 100,000 have caring responsibilities. British Telecom has a carers' policy which includes a definition of a carer and employees are encouraged to access information on local services via Carers UK and Help the Aged. British Telecom has supported the establishment of Employers for Carers, an interest group of like-minded employers which aims to identify and promote to employers and policy makers the business benefits of supporting carers in the workplace.

#### **4. Care for Carers Edinburgh: Stepping Out – Short Breaks**

This service provides respite to carers who have a residential break and who are provided with an organised and structured free group respite experience. This service targets adult carers in Edinburgh, with additional breaks provided for carers looking after a person with a **mental health illness**.

The need for respite remains the number one issue for carers in relation to the needs of the cared-for person but also for themselves. Care for Carers took part in piloting a series of short weekend breaks in 2000-2001 and the response to these pilots was overwhelming. Carers who come away on the Stepping Out service often do not have other regular breaks for themselves, or holidays, or overnight time out from the person they care for. Over the course of a weekend, two nights away, carers can relax and enjoy the company of others.

The Stepping Out service is delivered, managed and co-ordinated by Care for Carers. It is in the process of becoming a registered trade marked respite service and has been delivered for over nine years. A maximum of 25 places per short break are available and all breaks take place at the purpose built Low Port Education Centre in Linlithgow. The breaks are free. A full programme of organised activities is available during the course of the short break but carers are completely free to take as much time out as they need to do their own thing, or simply to rest. Referrals to the service are open and are publicised across all agencies. GP practices advertise the service on dedicated carer notice boards and the information is widely circulated around Health and Social Care Teams.

Since 2002 over 600 carers have taken part in a Stepping Out Short Residential Break. In addition the needs of minority ethnic groups can be catered for. All female Muslim groups have been able to attend the short breaks because the setting fits their needs and the supported structure of the weekend has female residential leaders. BME carers are supported during the weekend by the Minority Ethnic Carers Older People's Project (MECOPP).

Stepping Out is a unique service. The outcomes and feedback gathered from carers over the past nine years clearly evidence that carers benefit from this type of service in many different ways. It gives carers a sense of identity, supports their own health and well-being and enables them to feel they can cope better with their caring situation.

***"I benefited tremendously from the weekend. I knew how important it was to look after and think about myself, but this gave me the chance to see the long-term affects on others who had not done so. I had had quite a good week prior to the break but have had less good weeks since my return; the break has helped me to deal with the difficult times. It is difficult to know what the future holds but I am making the most of what is available to help me keep sane and to help my family."***

***"I have enrolled on and started a couple of courses for ME. I am also accepting the offers of help for me and my family. I would love to go on another weekend break to keep me reminded to look after ME!!"***

*“Feel I have recharged my batteries, found out about support I can access and I feel less isolated.”*

*“Rest and company. Good to talk to other carers with similar experiences and problems. Idea that you are not unique with these difficult problems. Found the stimulation to try new groups and have made valuable contacts. Will join Edinburgh Carer Support group, contact Queen Margaret College regarding course for carers. Take control of my life. Join a refresher course on stress management and relaxation. Warmth and friendliness of workers was greatly appreciated, no strain, the weekend has helped me enormously.”*

*“A chance to chill out and be pampered. Good to take away knowledge that there is people out there who care about carers. Knowledge that I am not alone and that there is a great strength of spirit amongst carers.”*

*“I will try and use the techniques which I was taught for dealing with stress, the whole weekend was very relaxing.”*

*“For the first time in years this weekend gave me a lift up, never felt so good in a long time. For the first time in a long time I was communicating better with people.”*

*“This weekend came suddenly out of the blue, it just appeared and I didn’t know what would be happening, so the whole weekend was a nice surprise. Talking to others about their situations and about my own was very helpful. Made me think about things a bit differently. They understand what I felt right now and knowing there was nothing I could do to change my situation but to try to keep going and accept the help that was being offered. I would like to say my thanks to all the staff and the leaders especially for the care and kindness they have shown me. I will always be grateful for the few days I have had here. They came at the very time I needed it.”*

*“It gives you time to evaluate your life and to realise that life is for living and each moment is precious. There is always a silver lining. Look forward with a quiet confidence and try to relax whenever I feel stressed.”*

*“I feel refreshed and happy. I’ll practice some Tai Chi every day.”*

*“Being my first time here, I did not know what to expect, but I could not have imagined how relaxed and at ease I would feel. I enjoyed everything about this short break. I felt as I have been really spoiled in every way. Seriously, I cannot thank you all enough. Beautiful weekend.”*

*“These weekend breaks are essential for carers. It gets them away from extremely difficult and stressful situations. They must continue.”*

## **5. City of Edinburgh Council**

**a) Partnership Working in Edinburgh:** This good practice example is based on a model of effective partnership working between the statutory and voluntary sector on



implementation of two local carer strategies in Edinburgh, Towards 2012 and NHS Lothian Carer Information Strategy. The approach taken to implement the two local carer strategies is through formal regular group meetings and by direct contact through subsequent meetings, phone calls, e-mail or report writing.

The carers' strategic action plan for Edinburgh has been developed through a planning partnership of stakeholders from NHS Lothian, Carer Organisations, Edinburgh Community Health Partnership and council departmental lead officers from Health and Social Care, Children and Families and Services for Communities. The action plan is now overseen and co-ordinated through the city's Strategic Planning Group for Carers.

The purpose of the NHS Lothian Carer Information Strategy (CIS) is to ensure carers are well informed and supported in their caring role by healthcare staff and local partner agencies. Carers can expect a standardised approach to their needs and recognition of the work that they do in providing care.

The needs of unpaid carers in Edinburgh were identified through the commissioning and consultation phase when the strategies were being developed. Implementation of the strategies includes developing joint procedures for the identification and referral of young carers by Health, Social Care and Children and Families Departments. There has also been the development of a business case for a short breaks bureau. A new carer's assessment tool has been developed and implemented on eAssess, in addition to the establishment of VOCAL's new person-centred planning service.

There is joint working with the City of Edinburgh Council Health and Social Care Department, Children and Families Department, Services for Communities Department, Lothian NHS Board, Edinburgh Community Partnership, VOCAL and MECOPP (Minority Ethnic Carers of Older People).

**b) Edinburgh City Council Carer Assessment Tool:** There was an identified need for an improved carer assessment tool through the development of the local joint carers' strategic action plan, *Towards 2010*. This involved consultation with local carer forums, carer partnerships and carer organisations as well as statutory stakeholders. The service is accessed by either making a referral or self-referral (via a carer's self assessment) to Social Care Direct, the central point for social care in Edinburgh. The service seeks to benefit unpaid carers in Edinburgh.

The carer's assessment is the template around which discussion of support for carers takes place. The assessor should always recognise the carer's knowledge of the cared for person and ensure that the carer's assessment has no negative connotations regarding the carer's competence to care.

The assessor should ensure that a carer's assessment identifies the outcomes that the carer would like to achieve. However, where there may not be resources or services to achieve these, there is an opportunity to document where services or resources have not been available and assessors are encouraged to do this to assist future strategic planning.



## **6. Dundee City Council**

**a) Carers Rights Day:** The Princess Royal Trust for Carers Dundee Carers Centre identified the need for information events from consultation with carers. Carers have sought opportunities to gain general advice from professionals independently of the person they care for. Often the carer acts as advocate/communicator on behalf of the person they care for and does not always have an opportunity or time to seek additional information on their own behalf.

The aims of this local event are to give carers information about their rights and to support them in their caring role. This event was held on Carers Rights Day in December 2008 and December 2009 and is expected to be held in December 2010.

Each carer has the opportunity to see two professionals with whom they would like a 'surgery' type private appointment. There are opportunities to have health checks and Red Cross First Aid advice about what to do in a health emergency. In December 2009 foreign language support was provided by staff from the Dundee Minority Ethnic Carers Project.

The council works in partnership with NHS Tayside, Dundee Carers' Centre, and the Red Cross.

**b) Short Break Guide:** This guide for carers and those they care for was produced by Princess royal Trust Dundee Carers Centre in partnership with Dundee City Council and NHS Tayside. The guide gives information and confidence to seek support, advice and funding for a short break. This guide provides advice to carers (and the person they care for) to allow them to arrange a short break.

This guide gives comprehensive information about Dundee based resources and was produced and developed by Dundee City Council and a former carer. A variety of private, statutory and voluntary organisations also contributed to this guide.

**c) Future Matters Group:** The Dundee "Future Matters" group organises an annual event for young people and their family carers (around February or March each year). There have been four events so far bringing together many organisations to allow young people and their families to browse information and speak to service providers. The focus of the event is reviewed annually and has previously covered topics such as housing and direct payments.

Group members plan, organise and participate in the event along with invited speakers and information stalls. The 2009 event featured a drama performance by young people which was recorded. This will be shared with professionals, young people and carers for education purposes.

The Group have developed a website <http://www.thefuturematters.co.uk/>. The website provides carers, young people and professionals with information which may help them negotiate a smoother transition to adult life.

## 7. Edinburgh Development Group – Supporting Older Families Initiative

The service supports older carers who have a son, daughter, or other family member, with a learning disability living at home. The majority of older carers are in the age range of 60-90 years old. However support is also available to sibling carers for a brother or sister with a learning disability where they have taken over the caring responsibilities when a parent has died.

The project aims to support older families to continue to care for as long as they wish to do so, responding to the individual needs of older family carers and people with a learning disability who are living at home with older family carers. The project development workers provide home visits and support to parents, siblings and other family members. Family carers and the adults with a learning disability are supported to plan for emergencies and also to plan positively for the future using a wide range of person-centred approaches and person centred planning tools. The project promotes the needs of older families with statutory and voluntary organisations to improve services to older family carers.

The need for the service was initially identified through the ‘Older Carers Group’ which is facilitated by Edinburgh Development Group. This is a regular forum attended by older carers who have had a lifetime of caring for a son or daughter with a learning disability. The project has developed new initiatives in response to needs identified by families during the lifetime of the project including a series of friendship workshops to support families to develop circles of support and community connections for the person with a learning disability; development of ‘My Life Books’ (a form of essential lifestyle planning (person centred planning) training on loss and bereavement for staff in respite provision, workshops on carer assessments, and a celebration of caring event.

The Edinburgh Development Group works jointly with the City of Edinburgh Council, social work, NHS Lothian and other statutory and voluntary organisations.

*“Being made aware of qualities I didn’t realise my son had.”*

*“Good course and very enjoyable.”*

## 8. Equal Futures: Circle of Support

**a) Circle of Support Kinross:** Eight years ago Lindsay was living at home with her parents and attending a day centre in Perth. When she first built her circle of support through Equal Futures it was easy to see immediately what one of Lindsay’s gifts was – how she connects with people within the community and how she can naturally form friendships. Lindsay invited a group of people that she already had a strong bond with to become the core of her Circle. Though most of those original members are still active, Lindsay has also made a special effort to bring in new people and build new friendships.

With the Circle's help Lindsay was able to express many hopes and dreams but first amongst these was to have a home of her own and for that home to be in Perth. Through the support of her Circle, however, she soon realised that just because she went to the day centre in Perth, didn't mean she had to live there. Kinross was where all her friends were and she'd actually be far happier living close to them. With hard work by all, Lindsay acquired her own home in Kinross which she decorated to her own tastes and filled with her own character, and arrangements were made for her to receive support daily to living independently.

The next challenge for the Circle was that Lindsay wasn't really being part of the community by travelling daily to attend a centre in Perth. They worked at finding more productive ways to spend her days locally. Her life is varied now – college, faith and light group, pottery, curling club and competitions, church groups, visiting friends and gliding. Lindsay is a member of the local gliding club and has just done her 144<sup>th</sup> flight.

Lindsay's very latest project is to get people who have poor mobility to enjoy the walking trail round Loch Leven, so with a little help from Kinross Partnership she has managed to get a local farm food shop to be the caretakers for mobility scooters so that people with walking difficulties can enjoy the views and wild life.

**b) Circle of Support – Perth:** Ewen and his parents had been away from Scotland for many years. When they returned they found out about Equal Futures through one of the group's family mentors and immediately loved the idea of trying to establish a Circle of Support. they found that asking people they had not seen for many years to be part of Ewen's Circle was not easy. That was where the Community Connector came in and it was he who successfully took on the job of asking people to become part of the Circle.

To the outsider, Ewen could be seen as someone who has very high care needs, but in reality he wants the same as the rest of us – people who love and care for him and who can enjoy with him all the many things that give him pleasure.

Each weekend he scoots around Perth in his powered chair investigating what changes have taken place since his last visit. Whether it's a new building rising up or an old one being renovated, or a shop changing hands, Ewen is the first to know about it.

With the support of his now well established Circle, Ewe has a series of goals, hopes and dreams that he is currently focussing on. One of these dreams is to move out of the residential unit that he's been in for a number of years now and into his own home within Perth or its surrounding areas. Another is to use his well developed computer skills to find some employment. Though he now has a very well established Circle of Support this doesn't stop him seeking new acquaintances and building new friendships regularly.

Ewen is a great connector and loves to pass on information and share what's been going on with his friends. Circle members say that you never leave his house without feeling welcomed, informed, relaxed and refreshed. Recently his Community Connector has helped him set up something new and existing using his interest in

computers. Together they are piloting a social networking tool call Tyze that safely lets Ewen and all the Circle members share what they are doing and keep in touch with each other.

## **9. Falkirk Council – Short Breaks Bureau**

Falkirk's Short Breaks Bureau provides this service for the benefit of adults and older people, and their families/carers, with an assessed need for short breaks/respice. It provides support to community care staff in identifying appropriate resources for the people they arrange services for. Individuals must have a community care/carer's assessment which identifies a need for short break(s)/respice in order to receive financial assistance from Falkirk Council. The Bureau can offer information and support to people who are self funding to identify and book an appropriate break.

Subject to assessment, including risk assessment, each individual is offered the option of one 'alternative' break per year which can be taken from a range of options for example, bus tour, caravan, hotel, bed and breakfast, holiday cottage and care home in a location of their choice. It is hoped that this will lead to an enjoyable experience for both the individual in need of care and support, and for the carer(s). Carers and individuals can take a break together, with support, if this is their preferred option.

The service is delivered through a dedicated booking service which is available during office hours, with back up provision by the emergency duty team for emergency respice. Single shared/carer assessment is carried out and if there is an identified need for respice/short break the assessor discusses the possible options with the individual and their carer. The assessor will be aware that there are a range of options available through the Short Breaks Bureau and will then refer to the Bureau giving details of the specific request.

There are a variety of private providers who work in partnership with the service to deliver the required options. This includes residential and nursing homes for people with physical and learning disabilities, mental illness, dementia and older people. It also includes private providers of holiday accommodation/breaks for example, Haven Holidays, Caledonian Travel, David Urquhart Bus Tours as well as owners of private holiday cottages, activity holidays and local travel agents.

## **10. Glasgow Association for Mental Health (GAMH) - Carers Support Service**

This service is for carers of people with mental health problems. Any adult mental health carer aged between 18 and 65 years and who lives within the five CHCP areas in Glasgow can access this service. Carers can self refer or be referred by others, for example, health, social work and other voluntary sector staff. This service aims to equip carers with the tools, skills and knowledge essential to support themselves in their caring role and to reduce isolation experienced by mental health carers. This service also includes BME mental health carers and other excluded groups.

The intention is for mental health carers to have more knowledge, awareness and understanding of mental health issues and recovery and to increase confidence in communicating with service providers and service users, while at the same time being aware of their rights as a carer.

It was recognised that the specific needs of mental health carers and barriers to seeking support, for example, stigma identified a need for support services for mental health carers.

Following on from service redesign GAMH carers support workers are now based within each of the service centres (one in each CHCP area of Glasgow). This has helped to develop and build on positive partnership working arrangements between the carers centres and also allows carers easy access to the other GAMH services and opportunities developed by the service centres. Many of the opportunities are delivered in partnership with other community resources. However, first and foremost GAMH carer services have been developed in partnership with the carer and will continue to develop around the needs of the individual carer. All carers participate in the partnership assessment tool which enables GAMH to personalise their support to their individual journey of recovery.

GAMH works in partnership with many statutory and voluntary organisations.

*“I thought I was the only one but there are lots like me.”*

*“For the first time in my life I feel my voice counts.”*

*“I know someone’s there for me.”*

*“It’s my time out and I enjoy a laugh and a change from caring”*

## **11. Glasgow City Council**

**a) Carers’ Services – Short Breaks:** The initiative provides anticipatory/preventative service intervention. There is a partnership approach to working which enhances social work provision alleviating pressure on it and on carers themselves. With shifting the balance of care high on the agenda, this initiative indirectly supports people with long term conditions to remain in the community. It aims to provide a minimum intervention to carers in order that they can continue in their caring role without detriment to their health as a consequence. It is a flexible service which gives carers and the people look after fast access and choice.

The service is individual and personalised and is achieved through the building of effective collaborative working relationships with a variety of local providers from private, statutory and third sector organisations. These providers include condition specific organisations to ensure appropriate provision to the cared-for person, for example, Alzheimer Scotland where the cared-for person has dementia or Barnardo’s APNA project where the care of a child with additional needs from a minority ethnic community is required.

The service aims to prevent crisis, hospital admission or reception into other forms of residential care. It can prevent failed discharge or alleviate a stressful situation. It can allow carers to attend medical appointments and, for example, see to personal business, and enables them to maintain their own emotional and physical well-being. It also allows participation in information sessions or training to equip carers with the skills they need to carry on caring.

Short breaks are an essential support to carers and as such this initiative is accessible to all carers across all care groups including young carers. The provision of short breaks accessed through the carer specific services are designed to enable carers to be relieved of a stressful situation without requiring an assessment or care plan for the cared-for person.

Evidence from carers frequently highlighted that just a little help at the right time can make all the difference in their ability to maintain their own health and participate in other life opportunities effectively, maintaining or improving their quality of life.

The service provided can average from one-off two to three hour periods (to attend an appointment) to one or two overnights for a number of weeks (to prevent admission to care). It can be one evening a week for ten weeks (evening class) or three hours to attend a carer's training class. It is very much a needs-led break person-centred provision. Where an intervention is to prevent further crisis and an exact end date cannot be initially identified, an interim period can be provided with regular review. This allows further assessments to take place for a longer term service.

Where respite is required on a continuous basis with no end date the short term intervention allows time for social work assessment for the cared-for person to take place and the regular respite for the carer to be built into their care package.

Recent analysis shows a slight decrease in crisis intervention and an increase in service uptake which allows carers to attend training and information sessions.

***"I now know where I can get help for myself and my relative."***

***"Very happy with the service provided, it was fast, efficient, effective and has made a huge difference in our lives."***

***"I feel more confident in caring for my dad and I know now where to turn for help."***

**b) Glasgow City Council's Working with Carers as Partners:** The training will be mandatory for health and social work staff within Greater Glasgow and specifically target staff working in the areas of learning disability, physical disability, and older people services, adult mental health, addiction services, and children and families affected by a disability. The training will also be available for voluntary sector staff from carers specific services and condition specific organisations. Equally, the training will be adapted to fit learning objectives of other service areas such as residential and day care, and community development.



This training will develop knowledge of the legislative and policy context for supporting carers and the main resources and support systems available to carers.

Since 2003 Glasgow has delivered training “Understanding Carers” for both social work and health staff. The training was optional and the learning objective was to raise awareness of challenges affecting carers in their caring role. The training was dated and although there were pockets of good practice across the city, a strategy was required to ensure the training was mandatory for relevant staff and that it reflected carers as partners. Work was undertaken to develop the module ensuring that it reflected policy drivers and local themes.

The training module is a one day programme and the pilot was jointly facilitated by social work and health trainers. Nominations for the events were invited from SW, health and the voluntary sector.

The training incorporated a strong session on values and encouraged staff to address and challenge attitudes and assumptions about carers. Similarly via case studies staff were encouraged to identify methods of working in partnership across agency boundaries, and with carers.

**c) Glasgow City Council Self Assessment for Carers:** All adult carers living in South East Glasgow are eligible to complete a self assessment form. The form is designed to enable the carer to reflect on their caring role and to consider what support needs they may have. A group of carers tested the form and following some modification a final version was agreed. Self assessment forms and “Are you looking after someone?” leaflets were distributed to key health and social care service points across the South East of Glasgow as well as to general public access points including libraries and community centres. There was a community event to launch the self assessment form and publicity in the local press.

The key aims of the project were to develop a simple assessment pathway to enable carers to directly access information, advice and support services and encourage more effective partnership working between statutory and voluntary services in identifying and supporting carers.

This pilot has resulted in a simple assessment pathway to enable carers to directly access information, advice and support services.

Most carers reported that they felt that the support they had received had improved the quality of life of the person that they cared for and had assisted them to continue in their caring role. There was most demand for emotional support, information and advice, and income maximisation. A large number of carers have also accessed carers support groups as a result of the pilot.

*“Very happy with the service provided, it was fast, efficient, effective and has made a huge difference in our lives.”*

*“I feel more confident in caring for my dad and I know now where to turn for help.”*

*“The information and help given in the local office was very helpful and I can go in at any time, they always listen and advise.”*

## **12. Inverclyde Carers Centre**

**a) Time-Out Inverclyde:** This is a health improvement project for carers in Inverclyde. The project sets out to improve awareness of information and support services in Inverclyde and also to look at the targeted health improvement areas of healthy eating, stress management and financial awareness. The project is targeted at carers living in the areas of Port Glasgow and Gourock although carers from other areas in Inverclyde are welcome.

The project is being delivered over a ten week period with each session focusing on a specific area identified by the carers.

The Inverclyde Carers Training Group has been involved in the initial stages of the project as it was being developed. Inverclyde Carers' Centre works in partnership with Inverclyde Community Health Partnership, Inverclyde Community Care Forum and Inverclyde Council – Social Work.

**b) Short Breaks for Carers:** Inverclyde Carers' Centre aims to give carers a break from their caring role to maintain their health and well-being, in addition to providing opportunities for carers to pursue activities and to develop social networks.

Carers can access a short break from caring up to four hours in a week. Carers identify their own needs and potential breaks and Inverclyde Carers' Centre staff contact local home care providers or the Short Breaks Bureau service.

Inverclyde Carers' Centre works in partnership with local home care providers and Inverclyde Council Social Work Services.

*“Has been a life line for me.”*

*“I am able to catch up on my sleep.”*

*“I have enjoyed having time to myself.”*

**c) Counselling:** This service is open to any carer 18 years or over registered with Inverclyde Carers' Centre. The counselling service is about change and empowerment and offers a safe, supportive environment enabling carers to discover more about themselves, explore difficulties and find solutions. Carers may bring issues to counselling either directly or indirectly related to their caring role.

The need for this service was identified by the response to support offered through volunteers at the centre and was further confirmed by a local authority wide Carers' Strategy consultation event.

Counselling provision is advertised widely through the centre's website, outreach surgeries, promotional materials and through partner organisations. Carers expressing an interest in the service attend a half hour initial consultation with a



counsellor from an independent company. At this initial meeting the counsellor and carer discuss their understanding of the counselling process and an initial assessment of the carer's needs are made. Centre staff can arrange short break provision through authorised care providers to help carers attend appointments.

Inverclyde Carers' Centre works in partnership with Inverclyde CHP and Inverclyde Carers Development Group (various partners).

*"I have felt very well supported by my counsellor during this very trying time and I am grateful."*

*"I feel it would be good to have a permanent counselling service at the centre."*

### **13. Inverclyde Respite Forum - Gie's a Break DVD**

This DVD aims to make people aware of the benefits of short breaks/respice by listening to the views of carers. This service is aimed at community care service users and carers, social work, health staff, and the general public.

Carers and service users are more aware of the range of services on offer and how to access these. Staff are more aware of the needs of users and carers and of the potential opportunities. Carers can identify with the feelings expressed by other carers in the DVD regarding their initial reluctance, guilt and fear about taking short breaks.

Inverclyde Respite forum works in partnership with Inverclyde Council Short Breaks Bureau, Inverclyde Carers' Centre, Inverclyde Carers' Council and Ardgowan Hospice.

### **14. Marks and Spencer**

Marks and Spencer understands the need to support staff who have to balance caring and working commitments. As well as time off for family emergencies, the company offers special leave of up to 4 weeks paid leave which may then be followed by three to nine months unpaid leave.

The company is also aware that there may be times when their staff would appreciate advice and support in dealing with a personal situation, either at home or at work. It operates a welfare helpful staff with advisors who are trained to listen and respond. If they cannot deal with the issue immediately they refer to a specialist who can provide support.

### **15. MECOPP (Minority Ethnic Carers of Older People Project) - Care at Home Service**

The service is aimed at those carers assessed as being in greatest need, for example, where the caring situation is at risk of breaking down and where there is risk of admission to longer term residential or hospital care. The service can also

provide intensive support following discharge from hospital or specialist support to facilitate entry to day care, residential short breaks, longer term care or end of life care in hospice provision. In certain circumstances, older people without carer support can also benefit from the service. The primary beneficiary of the service is the carer, although the needs of the service user are also addressed.

The need for this service was identified through analysis of MECOPP's ongoing casework and reinforced by feedback from minority ethnic carers and service users who had experienced difficulties accessing mainstream care at home services provided by the statutory, private and voluntary sectors.

The service operates an open referral system and currently does not charge. Each new referral is assessed by the service co-ordinator who undertakes an assessment of need and a risk assessment. All care assistants are bi-lingual and have knowledge of cultural norms, values and systems as they are from the same communities themselves.

The service provides assistance with personal care tasks, light domestic work to maintain a safe and clean environment, support to maintain social activities, preparation of light meals and shopping. Care assistants do not administer medication but will prompt users to take it. Prior to the service being agreed, a care plan is drawn up which specifies the tasks the care assistant will undertake and is agreed by all parties.

This service works in partnership with the City of Edinburgh Council and community care practice teams.

## **16. National Association of Adult Placement Schemes (NAAPs) – Shared Lives**

All adults aged 16 and over who might require some support to live within their own community can access the shared lives service. NAAPS aims to promote Shared Lives, homeshare and other small community services as an important resource to those seeking individualised services. Shared Lives arrangements are made by an agency (*a Shared Lives Scheme*). The scheme approves and trains the Shared Lives carers (*SL carers*), receives referrals, matches the needs of people seeking a service with SL carers, and monitors the arrangements.

Shared Lives arrangements are very different from more traditional forms of care, as features include people in shared lives having the opportunity to share in the life of the SL carers. SL carers use their family home as a resource and the relationship between the SL carer and the person placed with them is of mutual benefit.

All services are registered with the Care Commission. Currently there are 32 registered services mostly operating in the central belt, but some are also located in Aberdeenshire and Dumfries and Galloway. The majority are managed by local authorities but there are a few independent organisations that run a shared lives service. The services provide a range of provision to a diverse client group for example, people with learning disabilities, mental health problems, people with a diagnosis of dementia and people on the autistic spectrum.

Services can include long term with accommodation and support, short breaks or daytime support.

Shared Lives carers receive training prior to and post approval. Matching is key to a good Shared Lives arrangement and takes into account the requirements of the individual seeking the service and the skills and knowledge of the Shared Lives carer and practical issues, for example, where does the Shared Lives carer live and who do they live with?

NAAPS has developed policies and procedures specific to Shared Lives, as well as a learning tool “Learning the Ropes” that identifies 25 knowledge and skills statements that potential carers should achieve.

Shared Lives services are embedded in their local communities. They enable people to lead ordinary lives in the community, with service users feeling part of the Shared Lives carer’s family, having access to wider social networks and being integrated in the community. Shared Lives services can help local authorities to meet other new responsibilities such as building communities through providing opportunities and encouragement for people to become involved with the person they are supporting, with positive consequences for the wider community.

Schemes will work in a multi disciplinary manner involving other organisations or parts of social work services and/or health as required. It will not be unusual for OT, psychiatrist or psychology services, advocacy services and day support, to be working together to provide a support package. Schemes, not carers are registered with the Care Commission but carers play an active part in inspections though direct contact with the Care Commission officers.

## **17. National Schizophrenia Fellowship (Scotland) – NSF (Scotland)**

**a) Edinburgh Carers’ Support Project:** The Edinburgh Carers Support Project covers the whole of Edinburgh City and the surrounding rural areas of Edinburgh. Partners, friends and relatives of those experiencing any serious mental illness or suspected mental illness can access the project either directly or through referral.

Over the years, evaluation has shown that whilst carers still access the project for information and support, there is evidence that carers are now receiving more information from other sources such as Community Mental Health Teams, Community Psychiatric Nurses and the internet. However there still seems to be a lack of ‘personal support’ for carers which is where NSF (Scotland) Carers Support Projects come into their own. The Edinburgh Carers Support Project is still the **only** project in Edinburgh that offers one-to-one ongoing support for carers of those experiencing mental illness.

The project works with other statutory services such as health and social care and NHS Lothian, and other voluntary services.

*“I was so grateful a few years ago to get help from NSF (Scotland) and the Carers’ Support Project. I was in a bad place and it was a life saver – I will be eternally grateful.”*

*“I would like to say that the period we used the Edinburgh Carers’ Support Service was extremely beneficial to us. The meetings were well run and everyone was always given the chance to contribute. We feel it definitely helped us to deal with our daughter’s illness much more effectively.”*

**b) Dumfries and Galloway Carers Support Service:** NSF Scotland’s Dumfries and Galloway’s Carers Support Service is aimed at carers of adults experiencing mental illness.

The Carers’ Support Service provides flexible and skilful person-centred support for carers of people with mental health problems, and facilitate carers’ peer support groups. The service provides information on diagnosis and the systems of mental health care, and how to use them and, at the same time, informs carers of support systems that are in place to support them and provide help to make the best use of these services.

The service works closely with the health and social service agencies, the Princess Royal Trust for Carers, and carers.

*“If this group was not here I would feel isolated.”*

*“What has been particularly useful? Not feeling guilty to honestly say how I feel.”*

**c) Prospect:** NSF Scotland’s Prospect project is the result of a project developed by the European Federation of Associations of Families of People with Mental Illness (EUFAMI). It combines input from around 20 partnership organisation throughout Europe. There is no other programme like it in Scotland – NSF (Scotland) has the sole right to deliver the programme in Scotland. Carers of those experiencing mental illness have the opportunity to meet with others when they are able to look at the issues that are relevant to them directly.

The programme is delivered by four facilitators who are all carers in their own right over a residential weekend with a follow up weekend five months later. The programme is delivered to around 15 carers in a group setting, and together will explore how to ‘recover’ their own lives as carers. Some of the areas explored are recognising the pressures, identifying and acknowledging stress, loss and grief resolution, coping skills, support mapping, and change and goal setting. This is a very intensive weekend so an element of respite is present in order to maintain the wellbeing of all in attendance. The programme is, at the moment, open to carers from across Scotland via NSF (Scotland). It is the intention to open it up to other organisations across Scotland.

The programme addresses the needs of family members and friends in their own right, enabling them to gain confidence, and improve their coping skills.

*"I was one of the 14 carers who have a loved one with a severe mental illness. It was very much appreciated, this weekend away. Also good to meet others 'in the same boat'. I had a tear in my eye listening to so many sad, some horrendous, stories. Having been there myself with my son I know exactly what they are going through."*

## **18. NHS**

**a) NHS Fife:** NHS Fife has used Carer Information Strategy funding to run training sessions for carers caring for people who have had a stroke, have chronic obstructive pulmonary disease (COPD) and who care for people with autism. The Board funded respite and transport costs to reduce barriers to attendance.

The Board has also taken forward a Fife-wide inter-agency project providing manual handling training to carers in their own home.

**b) NHS Greater Glasgow and Clyde Hospital Patient Information Centres:** As a result of a feasibility study, the new Stobhill and Victoria hospitals have developed Patient Information Centres (PiCs). These drop-in services provide information and support to hospital users. Information is available in a variety of formats including literature and supported internet access for individuals to research their health needs. All information is approved by specialist staff in consultation with topic/disease specialist to ensure relevance and accuracy. The centres also provide specific health improvement services, for example, financial inclusion and stop smoking services.

A working group was set up to review carers' feedback and to develop an action plan to meet the needs identified. As a result, a weekly carers' drop-in service within PICs was established by local carers' centres to proactively promote carer support services, offer practice support and information to unpaid carers, and to undertake carers' assessments. A money advice drop-in service for patients and carers was also established.

**c) NHS Lothian e-Learning Carer Awareness Modules:** These modules are to inform NHS Lothian staff and independent contractors of the principles of the Carer Information Strategy (CIS). They will enable staff to learn these principles through a flexible, informative, and entertaining medium. Staff can access training at a time and place to suit them. There are two levels of training: a basic overview, and more in-depth.

All staff were issued with a bi-fold card through payroll advising them of the main strategic objectives of the CIS and giving contact details for third party organisations who could support carers. Summary documents were issued to NHS and partners.

E-learning is delivered using LearnPro software. All NHS Lothian employees have a training number to access training. Learners have to undertake mandatory updates on selected modules annually. New starts have to undertake certain modules as part of their core induction programme. Modules are supported and administered by NHS Lothian training department.

Decision about training content were taken in partnership with local authorities, CH(C)Ps, and third party organisations. Modules were delivered by third party carer organisation in partnership with NHS Lothian Training Department.

## **19. North Ayrshire Council – Short Break and Holiday Service**

This service supports a personalisation approach, providing a wide-range of supported short break holidays which reflect varied needs and aspirations. They are an alternative to residential respite. Holidays consist of week-long breaks, mid-week breaks, weekend breaks, overnight breaks and day breaks. This service is available for people with learning disabilities who are interested in an alternative to residential respite and for people aged 18 or over who may also have complex needs, challenging behaviour, physical disabilities or autism. Carers will benefit from a break while the person they care for has a short break or holiday experience.

A series of public meetings was held with users and carers, social services staff, health services staff and care providers who confirmed the need for the service, obtained views on how to design it, and gave an indication of possible usage. Both carers and the people they care for wanted holiday experiences, supported by well-trained staff and at a reasonable cost.

Holiday participants plan the holiday and programme of activities with the carer and holiday providers prior to the break. Care providers will provide qualified staff and staffing ratios appropriate to people's needs. Social services cover all care staff costs including the cost of undertaking activities with people in need of care. People receive the same level of support that they would receive if they were attending residential respite. A financial contribution is also made, similar to that which would apply if they used residential respite.

People with complex needs can now access the holiday programme. Carers also have confidence to plan holidays for themselves, confident that the person that they normally care for will have all their needs met while they also are on holiday. People have choice in where to go and what to do for each short break.

***“My son has not stopped talking about it. He was just in the door and said he is looking forward to his next break.”***

***“For the first time I can book a holiday in the knowledge my daughter is being well cared for.”***

***“It’s brilliant that my son can go with people his own age and potentially make life- long friendships, which he is missing out on.”***

***“Although my daughter is blind, has a hearing impairment and requires a wheelchair, she thoroughly enjoyed her break at Alton Towers. It had always been a dream of hers.”***



## **20. North United Communities (Glasgow) – Family/Carer Support**

This service is available for families who are affected by substance misuse within Glasgow North CHCP. It aims to adopt a holistic approach to supporting families affected by addiction.

The project works in partnership with families to assess their needs and identify the issues that are affecting them. For the person with an addiction the aim would be to increase opportunities for the person to be enabled to move on from their problem drug use, towards a drug-free life.

The need to support family/carers was identified and co-ordinated at a local level through the work of the North Addictions Forum. Furthermore, in terms of assessing the needs of family/carers affected by addiction, increasing the numbers of carers' assessments was identified as a strategic priority by Glasgow City Council.

The service is provided by a family/carers support worker who has been employed within the North United Communities Youth Project and funded through Fairer Scotland.

The worker will provide support to families referred to the service for support. It is anticipated that the role will enhance current service provision by enabling greater co-ordination of existing resources to provide an anticipatory support service.

The family/carers support worker provides support by carrying out assessments of families/carers to identify the issues that require to be addressed and what supports can be accessed to meet these. A clear referral system so that agencies and organisations understand the services on offer and how these can be accessed has been established. The support worker will also maintain accurate records and track referrals to assist with internal planning and external reporting.

North United Communities work in partnership with North Glasgow Addiction Forum, North Glasgow Addiction Services, North Glasgow Carer Support Team, North Glasgow Youth Health Services and North Glasgow Youth Stakeholders Group.

## **21. Parkinson's Disease Society (PDS) - Six Week Course for Carers**

The Edinburgh Branch of the Parkinson's Disease Society has recently developed a six-week course for carers of people with Parkinson's. The course demonstrates the need to balance the needs of the person needing care with the needs of the carer, and to provide a mixture of practical information and discussion of emotional and relationship issues raised by caring. The course covers:

- Information about Parkinson's and its treatment
- community care structures and benefits
- Discussion of the impact of caring on relationships
- Forms of stress management and fun activities

Respite cover was provided for participants if they need it to participate. PDS would welcome the provision of courses with similar content elsewhere in Scotland, and believes that centrally provided information resources and training must include both emotional and practical elements.

## **22. Perth and Kinross Council**

**a) Perth and Kinross Council's Life Coaching:** This was initially a pilot service in Perth and Kinross where a life coach worked with 20 carers to enable them to regain control over their lives. Carers must have an assessment of their support needs, and where carers are assessed as needing help to regain some control, or where they have recently been bereaved and need support to rebuild their lives, they may be referred for a life coaching course.

For the initial pilot, social workers were asked to identify carers whom they thought might benefit. Those carers were then referred to the life coach, who made contact with the carers and arranged the sessions and the meeting place, to suit the individual carer's circumstances. The usual schedule of life coaching was 12 sessions, each of two hours, once a fortnight. However this had to be very flexible to fit around carers' health and other commitments.

Each carer set between one and three goals throughout their sessions and all achieved success in their chosen areas with a plan of action established to continue moving forward after the programme.

With the next group of carers it is proposed to create a buddy system which would allow each carer to be paired with another carer to provide continued support and accountability, building community capacity and creating a coaching culture. This will also support carers to socialise outwith their caring role with people who understand their pressures and challenges.

Perth and Kinross Council works in partnership with Your Launchpad (the life coach service).

***"Felt relaxed and able to talk frankly about what I felt and want to reach targets."***

***"Easy to talk to. Listened to my fears and encouraged me to face them."***

***"More than my expectations. My first thoughts were a bit wary of what to expect and I just thought that she would give me some ideas to think about to help me get my life back after years of caring. The actual was very different. She helped me negotiate through everything, from my past issues right up to the present day and was fully supportive."***

***"For years I have waited for this opportunity for someone to help me to turn my life around. I am experiencing small good changes already in my life."***

***"I expected nothing, was full of doubts but thought 'I will give it a go', I am***



*very glad I did. Like I have already said, I did not expect much when starting this course. I was wrong. I began to call her my friendly happy bully (and I mean that word in a lovely way). She saw to it, her expertise, her life coaching, that I am back on course pursuing my hobbies which I had almost given up. I am very grateful to her.”*

*“I started off feeling a bit awkward and the first few weeks were difficult at times facing things from my past but as each stage progressed I felt I was becoming stronger. I have been able to ‘put closure’ to so many parts of my thoughts of the past and that has been very positive and is helping me to move forward. I have a new found confidence and am really looking forward to my future as the coaching has helped me to develop new coping mechanisms. I will no longer be put upon and will always know that I do have the right to make choices and not feel guilty about my decisions. I have my ‘sparkle’ back. Thank you so much.”*

**b) Perth and Kinross Council’s Carers Conference (Short Breaks/Respite):**

Perth and Kinross carers’ conference aims to support carers and stop them feeling isolated. The service seeks to benefit carers by providing them with peer group support as well as an opportunity to gain information and advice about a number of issues. This is for adult carers of adults and aims to involve carers in the planning and development of services.

A carers’ conference is held twice a year. This is the main method of consulting with carers and involving them in planning. At the first conference in May 2007 carers were involved in the development of the Action Plan for the Carers Strategy 2008–11. The carers made it clear that many of them, rather than booking a week/fortnight of residential respite, prefer to be able to have a few hours once a week, or a fortnight, to enable them to follow up other areas of their life and keep in touch with friends and family.

Carers access the service by first having an assessment of their support needs. Those carrying out the assessment try to support carers to maintain a life of their own and offer this service as a way forward.

In qualitative terms, this type of respite is enabling carers to maintain other aspects of their social lives and that, in turn, helps to maintain their emotional health and well-being. In the Carers Satisfaction Survey, the carers were also asked if they felt able to continue with their caring role. 64% responded positively to this question. The provision of flexible, daytime, personal time to carers is seen as an essential tool in maintaining their ability to continue to care.

Perth and Kinross Council works in partnership with voluntary organisations such as The Princess Royal Trust for Carers and other statutory agencies.

*“I have complete peace of mind.”*

*“I could not have asked for more or better help. A first class system. They have been excellent and are still helping me to cope.”*

**c) Perth and Kinross Council's Complimentary Therapies:** Perth and Kinross Council's complimentary therapies projects seeks to provide a service that will maintain carers' emotional health and wellbeing while they are caring. Carers must have an assessment of their support needs. Where carers are showing signs of stress as a result of their caring role, then they are offered six free sessions of complimentary therapies. This is specifically time for themselves.

As a result of an evaluation, and the carers' comments, this led the council to mainstream the service and they are currently developing an approved provider list of therapists, so that carers can choose their therapist and access someone closer to their home. This service is one which enables the carer to maintain his/her health and wellbeing and thus helps to avoid the gradual decline into isolation and depression which affects so many carers.

***"Was very helpful to me at a time when I was feeling down. Looked forward to therapies and counselling because I knew I would feel better afterwards."***

***"I felt very much better after my visits to the Norwell clinic; both the massage and the kind counselling I received there. I do feel fortunate to have had the chance to benefit from this."***

***"I had lost myself as a person and was living others lives for them. I had no thoughts, feelings or emotions as I'd felt they were unimportant and had been buried. The clinic helped me become aware of and respect myself. I'm no longer on automatic pilot. Thank goodness there is help available."***

***"This service... should be available all the time – not just six sessions. Caring is so demanding and everyone has a different 'load' to cope with. We should not have to wait until we are really low. Having these treatments regularly would be wonderful and give carers something to really look forward to. This would help avoid the lower times and everyone would benefit from a happier carer. Why wait until they are wrung out?"***

## **23. Quarriers Break-Away Fathers Project (Dumfries)**

The over-arching objective is to improve life for families who have a disabled child/young person by developing better relationships between fathers and their children (including siblings) and men and their partners. Fathers can become more involved in their children's care at home, education at school and future care plans. There is an improved understanding between men and their partners enabling the identification of stressors, better management of stress and better sharing of roles and responsibilities related to their child. This service provides a voice for fathers through informal advocacy which helps to improve the father's relationship with a range of professionals.

Male social workers within break-a-way fostering service (who were also fathers) became aware of how marginalised fathers were from the care and planning for their disabled child. It is accepted that mums tend to take the main role in the care of their child and services tend to be focused around them and their availability. Medical,

education and social work meetings happen during the day when dads work. Significant time off to attend meetings and appointments can affect the father's income and there seems little compromise from statutory services who have a duty to include the views of both parents when, for instance, an assessment of need is carried out.

The Fathers Project started as a pilot in Dumfries. Within a short period of time, the group started to meet with greater frequency and then expanded to Stranraer (75 miles from Dumfries). The group helped to crystallise the needs of fathers and quickly established that these dads didn't know their disabled child as well as their non disabled children. Father and child social activities and events were developed alongside "whole family" events and activities.

The work has steadily progressed beyond groups and now encompasses a range of different supports including advocacy, training and information. Currently the project is managed by a project co-ordinator working across the region with the support of a volunteer dad and a project assistant who works sessionally.

This project works closely with colleagues in social work.

## **24. Renfrewshire Council – Carers Self Assessment**

Renfrewshire Council launched the Carers Self Assessment in early 2008 which was devised in consultation with carers and the Renfrewshire Carers Centre, and has been very successful. For example, another local authority asked to look at Renfrewshire Council's Carers Self Assessment and adapted this for their own use.

Renfrewshire Council has devised and launched a comprehensive training programme for carers. Prior to this Renfrewshire Council have ran courses on dementia, strokes, stress, coping with strong emotions, etc. Feedback from these courses have informed shaping the programme of future courses. Feedback is also provided to health/local authority services on carers experiences of health interviews and services to inform change.

Training for Carers In Renfrewshire was 100% carer led and completed as a result of an extensive consultation exercise with 58 carers, with different caring situations, and with the Renfrewshire Carers Centre. Training for carers in Renfrewshire is based on Carer Information Strategy funding and was launched formally in January 2010.

## **25. Scottish Consortium for Learning Disability (SCLD) – Local Area Co-ordination (LACs)**

This is a values-based approach to supporting both individuals and families by providing information, signposting and guidance. The approach is based on a set of principles that promotes the rights of disabled people and their carers to be involved in the life of the community. LACs work in a way that is determined by the needs of the individual and the family that they are working with. It is a long term relationship

and LACs work with people through all stages of their lives. This service also prevents crisis by supporting people to access the right services at the right time.

Local Area Co-ordinators work directly with individuals with learning disabilities, their families and their communities. They work across Scotland and most are currently employed by local authorities through social work departments. Most of the LAC services in Scotland operate with a flexible and open approach to access and is available for children and adults.

The need for LAC in Scotland was first identified in 'The same as you?' (2000) review of learning disability services in Scotland. In this it was recommended that local authorities employ LACs to work alongside individuals and their families in their communities. Since then LACs have been recognised as good examples of personalised, preventative approaches to working with people with individuals and families.

LACs are employed by local authorities, health boards and voluntary sector organisations. LACs can help to facilitate and build better access to all agencies and through their remit to promote inclusion.

***"I care for my son who is now 21 and has verbal dyspraxia and learning difficulties. I have been battling with authorities since my son was two years of age to ensure he receives the services he is entitled to, but that is another story."***

***"I have found the support of our Local Area Co-ordinator invaluable. She is able to cut across local authority departments and has a thorough knowledge of all the services available. I have found she is able to anticipate what help and support we need and come up with solutions and ideas that we are not aware of. She has always made herself available to us and been cheerful and positive. Since her intervention into our lives the constant 'battle' and my frustration at trying to gain the services that my son is entitled to has been lessened."***

## **26. South Lanarkshire Carers' Network**

South Lanarkshire Carers' Network (SLCN) aims to provide a voice for unpaid carers at all levels of strategic planning and achieve outcomes for carers which are reflected in national outcome requirements. This service enables unpaid carers to participate by providing training, travel and care expenses.

Carers drive the agenda for the SLCN which is to further the aims of carers. All carers and former carers are encouraged to utilise their expertise in the planning and delivery of services which affect their lives. The Network is run by carers for carers.

SLCN employs three staff and involves 19 directors who are involved in strategic planning from locality through the Carers' Strategy joint performance report, joint service planning, healthcare partnership, public partnership forum, long term conditions programme and community health partnership operating management group.

South Lanarkshire Carers' Network works in partnership with South Lanarkshire Council, NHS Lanarkshire and the The Princess Royal Trust Lanarkshire Carers' Centre.

## **27. South Lanarkshire Council – Time to Think About**

The support offered is to older family carers, age 50 and over, of adults with learning disabilities. This service aims to increase awareness of the needs of older family carers and support carers in thinking about planning for the future.

Information workshops for carers have been held across South Lanarkshire on the Role of Social Work, Housing Options, Legal Issues, and Direct Payments. Telecare is planned for the next workshop. The social worker works with Glasgow School of Social Work (Carers and Service User Network) in putting together a database in order for carers across South Lanarkshire to have the opportunity to become involved in the teaching of social work students. Alternative therapy sessions for carers at each of the resource centres in South Lanarkshire have also been set up so that carers can access the therapies in their own community.

A 'Time to Think About' resource pack has been developed and sent to carers and colleagues. The pack is intended to support carers about future planning, listing housing options, and legal options, but also informs carers of the support available for them. This accompanies a wider piece of work, the six area teams (for adults in South Lanarkshire) engaging and offering visits to older carers to discuss future planning, offer support and provide information.

A Learning Disability Partnership in Practice Group for carers has also been set up and this group meets six times a year working through an action plan with supporting carers of adults with learning disabilities at the heart of this.

South Lanarkshire works in partnership with The Princess Royal Trust Lanarkshire Carers' Centre, South Lanarkshire Carers' Network as well as with other voluntary sector partners.

***"I am so pleased to have you at the end of the phone. I don't know where we would be without you."***

***"They trust you and they know they can rely on you."*** [An older carer speaking about the support offered to other older carers].

***"I had no idea that I didn't have the legal right to make choices for my daughter. Thank you for this information and your advice."***

***"We have never been able to think about housing for our daughter until now. Thank you for your support and the information you have given us."***

## 28. Tayside Carers Support Project - Liaison and Collaboration Initiative

This initiative with Carseview Centre, Dundee (The Carseview Centre is the Mental Health Service Hospital for Dundee) was implemented in 2003 in order to improve communication between carers and staff at Carseview Centre, to bring about positive tangible benefits for both carers and service users.

This service is available for anyone who cares for a relative or a friend with a severe and enduring mental illness such as bi-polar or schizophrenia, severe depression, or personality disorders who live within Dundee City. The diagnosis does not have to be specific to any of those listed as any serious illness qualifies for help from this project. The criteria is that the person who is cared for has to be between the age of 18-64. Access to the services is via the Tayside Carers' Support Project.

There is ongoing fostering and commitment of senior managers to open honest communication and dialogue between service providers and carers.

Overall, all of the changes implemented are extremely beneficial for carers as well as service users. Carers are very pleased that ward activities have been reviewed because boredom can be an issue for many service users.

***"The staff have been very helpful."***

***"Don't feel like I am bothering the nurses anymore."***

## 29. The Princess Royal Trust - Glasgow South East Carers Centre

**a) The Moffat Project – Preventing Crisis for Carers:** This project has two distinct target groups: one is staff within an acute hospital setting and the other is carers of in-patients within an acute hospital setting. This provides hospital based staff with the necessary skills to create a robust infrastructure for the identification, recognition, support and signposting of carers.

The project gives hospital based staff a greater understanding and awareness of the needs of carers and the important role carers have in society, through bespoke carer awareness training. Staff have also been made more aware of their own responsibilities in relation to the identification of carers, carers' rights and legislation. Carers receive the greatest benefit from the project through early identification, acknowledgement of their caring role, involvement in discharge planning and signposting to support services that support them to care for their loved ones.

The focus of this work stems from carers' centres experiences of the challenges around supporting carers presenting in crisis, the impact of delayed discharges on patients and carers, and readmission rates.

The pilot project is being independently evaluated by Glasgow Caledonian University's School of Health and Social Care. This will provide both qualitative and quantitative research.



*"I found the Moffat worker very helpful and understanding. She was quick to provide assistance/advice I find her very supportive. She is easily contacted which is of great importance. She does a very worthwhile job."*

*"I would not have known about any of the support that was available for me if it was not for the help at the carers centre."*

**b) The Princess Royal Trust's Relaxation and Stress Management Training, West Dunbartonshire:** This service seeks to benefit adults who are in a caring role and who are suffering from stress or stress related conditions. The carer must live within West Dunbartonshire or be caring for someone who does. The need for this service will be identified through offering and carrying out a carer's assessment.

In November 2007, carers of West Dunbartonshire began carrying out carers' assessments in partnership with West Dunbartonshire Council. The carers' centre and the local authority's Single Shared Assessment (SSA) team worked together to develop a process which was meaningful and user friendly for both the carer and those carrying out the assessment. This process, with the carer's consent, allowed the carers' centre access to information about the carer. All carers who contact the carers' centre are offered a carer's assessment and support plan. By carrying this out with the carer their individual level of need can be identified.

Carers of West Dunbartonshire have offered individual complementary therapy sessions to carers for some time. These sessions provide the carer with one to one individual treatments which can help alleviate many health issues, not least stress and anxiety. The impact and benefits of these sessions are evaluated with each carer.

The service is delivered as two training courses. Carers are asked to complete an application form. Prior to facilitating training the therapists are informed of which carers will attend which allows the training to be tailored, as far as possible, to each carer's needs and allows consideration of suitable venues and times, for example, offering evening training to carers who are in employment or education.

The carer is taught how to use these techniques safely and to maximum effect, by a qualified clinical aromatherapist, as a way of complementing conventional treatments. The carer can then use their skills for themselves to treat stress and assist with relaxation as well as using them to benefit the person that they are caring for, for example, to reduce agitation in someone suffering from dementia or to reintroduce touch within the relationship.

This programme of Stress Management training provides carers with an understanding of stress mechanisms along with effective tools for combating stress. It is designed to promote mutual support and decrease feelings of isolation, frustration and hopelessness. The programme was developed by a former carer who is now a Stress Management Consultant.

When carrying out a carer's assessment and support plan, PRTC work in partnership with the local statutory agencies and local SSA team. For the purposes of training

PRTC works in partnership with a qualified clinical aromatherapist, stress management practitioner and health professionals.

*“I would definitely tell other carers to attend – it’s so beneficial and gives you a great insight into your own stress and health.”*

*““I got a great deal of emotional support as well as great practical ideas about stress and relieving it. It was good to talk to others who understood and to know I’m not alone.”*

*“The facilitation was fabulous – a great pace so that a lot could be covered but not rushed. I have valuable tools now to combat stress.”*

*“This workshop is a must for carers. I found it very healing somehow. I would encourage other carers to come and enjoy. I would love a follow up workshop.”*

*“My husband has had a stroke, I like to massage his hands and arms as it stops them being so rigid. I told my GP about the course and he thought it was a great idea.”*

### **30. VOCAL (Voice of Carers Across Lothian) - Carers Counselling**

VOCAL supports unpaid carers caring for family, partners or friends in need of help because they are ill, frail, have a disability or are affected by someone’s alcohol or drug use. The service seeks to alleviate the emotional impact of caring and support carers to manage the mental and emotional stress of the caring role. The emotional impact of caring for a relative or friend can be immense. Caring for a partner or relative with dementia, with a severe disability or long term condition, or child with special needs can often affect a carer’s emotional well-being more than their physical health.

VOCAL discovered the depth of the emotional needs of many carers in routine information and advice work which includes providing a ‘listening ear’. It became apparent from many carers that the emotional impact of caring was the single biggest issue in their lives, and that an adequate professional response required the support from trained professional counsellors. To meet the emotional support needs of carers in greatest need, VOCAL in Edinburgh developed a Carers Counselling and Groupwork Service in 2000.

The service is co-ordinated by an experienced manager who is also an accredited counsellor, and is provided by eleven professional counsellors - ten female and one male - all of whom have completed counselling training to diploma level. Counsellors give their time free in return for VOCAL meeting their clinical supervision costs. Each counsellor offers at least three weekly counselling sessions, many offer more. Counsellors are offered continuing professional development opportunities through invited speakers and short workshops at quarterly team meetings.



In 2009, the service received over 100 referrals, offered 1092 counselling sessions to more than 60 clients and received a high 79% client attendance. Carers ranged in age from 21-84 with the majority being women over 50 years of age. The percentage of male carers using the service has increased to 28% from 20% in the previous year.

VOCAL regularly attends the Edinburgh Voluntary Sector Counselling Services Forum and Edinburgh's Placement Managers meetings.

***"I would not have got through the last year without my counselling at VOCAL."***

***"Helped me understand the roots of my problems which in turn eased my caring load."***

***"Friends and family depend on me so I couldn't speak to them. I'd recommend counselling to everyone."***

### **31. VSA (Voluntary Services Aberdeen) Carers Services Aberdeenshire and Alzheimer Scotland**

**a) VSA Carers Services Aberdeenshire:** This service aims to offer advice, information and support on all aspects of caring. The aim is to promote a greater awareness of carers and their needs, identify hidden carers and improve carers' access to resources. This service is for all carers living in the Deeside area.

Questionnaire regarding support/social groups was issued to all carers on the VSA database. Through these questionnaires and from speaking directly to carers, several needs were identified, including: the need for carers to have a break from caring; an opportunity for carers to meet up with other carers socially; receive advice and support; and the need for recreational activity.

A relaxation/gentle exercise group was identified which might meet the needs of carers. It was something fun that gave carers time away from their caring role and had the added benefit to carers' health. Carers would have the opportunity to socialise afterwards. Information and support could be given by a VSA/Alzheimer Scotland worker if required or requested. Transport could be provided to enable carers living in outlying areas to attend.

Carers feel a physical improvement from doing the exercises and also feel more relaxed after their class. There is an opportunity for socialising and carers have met new friends through attending class. Some carers have begun to take an interest in the practice of yoga and have started to study books on the subject, coming along each time with new questions to ask.

VSA works jointly with Alzheimer Scotland and a local yoga teacher. Information on this service is also sent to Aberdeenshire Council Social Work Department, NHS and local GPs.

*“ It is great to have a regular time to relax.”*

*“It has been most beneficial to all concerned, not just quality of yoga teaching but also the social aspect which everyone has benefited from.”*

**b) VSA Carers Centre Aberdeen:** This service is to provide advice, opportunity and support to carers in Aberdeen city. This began as a pilot based on the ‘lifestyle management’ delivered by the Thistle Foundation.

The VSA Carers’ Centre gives carers in Aberdeen the opportunity to pause, think and begin to plan a lifestyle which suits them, providing more balance and well-being for the carer, for the person cared for, and perhaps others in the family too. The course encourages carers to understand their life as a carer and consider choices and perhaps take small steps to improve their health and well-being. It offers the chance to meet and share helpful ideas with other carers as well as to hear from the carer centre facilitators how making new connections and choices have helped others.

Carers can enjoy this chance to meet other carers in a similar situation who want to take a look at the connections, choices and changes in their lives. The course therefore offers fun as well as learning, perhaps leading to friendships and a new network of support which can continue after the course.

The VSA Carers’ Centre works with a life coach.

*“It has made me more concerned about my own needs and requirements in other words to have some ‘me’ time.”*

*“Being with other carers made me realise that I am not alone which made me feel less isolated.”*

*“I felt it was o.k. to stop trying so hard – more able to step back a little and focus on the positives.”*

*“A very well designed course (balanced) informative, useful tools, techniques to take away with you and carry on into the rest of your life. Helpful, practical and motivating.”*

*“The support and information I received throughout the course and from the staff at the carers’ centre helped me to continue my caring role, without it, I am not sure how things would have turned out.”*

**c) VSA Carers Centre Male Carers’ Events:** This service provides an opportunity to bring together male carers to discuss what services are working and where there are shortfalls. Representatives of the local authority and NHS help provide this service.

Male carers expressed their isolation and desire to meet with other male carers. Many events held at the centre attract mainly female carers and male carers said they would like to meet as a group socially with some constructive discussion.

The group agreed that regular events, perhaps once or twice a year would be beneficial with the opportunity to meet the 'decision makers' for health and local authority services, rather than to have monthly group meetings.

VSA works in partnership with Aberdeenshire Council and NHS Grampian.

## Part 2 – Young Carers Good Practice

### 32. Action for Children, North Lanarkshire Young Carers Project

**a) Schools Project:** Through a Service Level Agreement with North Lanarkshire Council, Action for Children provide young carer Education Link Workers based in secondary schools throughout the local authority.

These workers provide vital support to both young carers and school staff and have helped to identify many hidden young carers and link them in to support both within the school setting, core project and local community.

Education Link Workers provide awareness raising sessions to all first year pupils, develop group work programmes in partnership with school staff, attend pupil support meetings and joint assessment teams meetings, where necessary and are an ongoing support for young carers within the school community.

**b) Young Carers Health:** Through their Carer Information Strategy, NHS Lanarkshire have funded Action for Children to appoint two outreach workers to work closely with health teams to improve health outcomes for young carers. These workers also develop presentations to raise awareness of young carers' health needs within identified health teams and support the development of specific health information for young carers.

Young carer assessments highlight that many young carers lacked an opportunity to discuss their own health issues and identify ways to introduce positive changes in their lifestyles that would impact on both their physical and emotional well-being. In response the project has worked with public health practitioners to deliver health focus groups to young carers on stress and relaxation, feelings and emotions, healthy eating, body image, smoking and alcohol, sexual health, drug awareness and oral health.

**c) Young Carers Training:** The Action for Children, North Lanarkshire Young Carers Project has an ongoing partnership with Coatbridge Fire Service who offer a five day 'Fire Reach' Programme which has been developed specifically for young people, but is slightly modified for young carers. The programme provides young carers with the opportunity to learn about self discipline, working as part of a team, first aid, fire safety as well as working directly with fire fighters and performing a Fire Drill, dressed in Fire Fighter's uniform.

The project also works with colleagues in North Lanarkshire Council's Community Learning and Development Section and offers young carers the opportunity to participate in the North Lanarkshire Challenge which is a programme of activities for young people between 8-14 years which promotes social and personal development. Based on the Duke of Edinburgh Award it encourages children to develop new skills, take part in sporting and outdoor activities and become involved in some voluntary work in their schools and community (which young carers do every day through caring).

The Project also currently works in Partnership with Landed Peer Education Service - who train young people from age 16-22 from Lanarkshire to pass on information about drugs, alcohol and sexual health to other young people in the area. This is extremely beneficial to young carers who may have missed vital sessions within school or who feel inhibited to ask their own questions about drugs or alcohol because of parental misuse.

### **33. Dumfries and Galloway Young Carers Strategy**

The PRTC Dumfries and Galloway Young Carers Project, with Dumfries and Galloway Council and NHS Dumfries and Galloway have produced a Young Carers Strategy for all young carers in the region. A multi agency strategy implementation group has been established to oversee the action and delivery of the strategy.

The overall purpose of this strategy is to act as a practical tool to improve the support for young carers throughout Dumfries and Galloway. It does this by providing a framework to enable better interagency working within current statutory guidelines, setting out to identify key local issues for young carers, raise professional awareness and enable a life balance for young carers.

### **34. Dundee Carers' Centre - UPBEET Project**

The UPBEET Project supports older young carers aged between 15 and 21 who are having difficulties with accessing education, employment or training opportunities, often because of their caring role.

The project provides focussed one to one support to enable young carers to access work, education or training, and to sustain them in this. The primary aims of UPBEET are to identify and reduce the extent of inappropriate caring responsibilities taken on by young people and to produce positive outcomes for the young people.

The service benefits from being situated in Dundee Carers Centre alongside a range of other projects. It is closely linked with the Young Carers project, which provides access to a dedicated Family Support Worker and other groups and activities. UPBEET also benefits from the centre's Welfare Rights and Information Teams who can provide focussed support for benefits and other identified needs. The main focus of the work is intensive one to one support, and there is also a strong emphasis on formal, accredited training opportunities.

The UPBEET Project is part of the Discover Opportunities Partnership in Dundee which co-ordinates a wide range of organisations to provide work-focussed support. As a result of this, UPBEET is able to work closely with other partner agencies to tailor support effectively to the young carers.

The majority of young carers have accessed some kind of positive destination and sustained their involvement. Most UPBEET young people have gained some form of accreditation, including through Youth Achievement Awards. A significant amount of awareness-raising work has been carried out in local schools, colleges and other agencies. UPBEET has also piloted volunteer placements within the Carers Centre

for UPBEET clients. A national conference was held to highlight working with young adult carers - UPBEET young people took part in planning and leading on the day.

### **35. East Ayrshire Carers Centre - Alpha Venture**

East Ayrshire Carers Centre operates Alpha Venture Employability Centre to support young carers into employment, education or training. The project is funded by Inspiring Scotland and over the next 10 years it aims to support 1000 young carers.

Alpha Venture Employability Centre operates from Dalmellington House, which is East Ayrshire Carers Centre's Social Enterprise company. Dalmellington House has been renovated to a very high standard to operate as a luxury 'boutique hotel', which provides carers from all over the UK with respite breaks at highly competitive prices.

Alpha Venture employs five staff including a Chef/Trainer, Housekeeper/Trainer, Guest Relations Officer/Trainer, and two Alpha Venture Support Officers/Trainers who manage the day to day running of Dalmellington House as well as the training and support of the young carers, as Alpha Venturers.

Alpha Venturers receive work experience at Dalmellington House in hospitality and catering and are provided with the opportunity to undertake SVQ Qualifications and ASDAN awards (Award Scheme Development and Accreditation Network). ASDAN is an educational charity that promotes the personal and social development of learners, to enhance their self-esteem, their aspirations and their contribution to their community.

East Ayrshire Carers Centre works closely with schools, the More Choices More Chances forum, colleges, ASDAN, SVQ and a range of training providers and employers in the area.

***"This is a great venture, they really understand the problems we have as young carers and the help and support they give us is fantastic. I feel really motivated now to work hard and find a job."***

### **36. East Ayrshire Council – East Ayrshire Carers Centre**

Having identified a lack of provision for young carers affected by parental substance misuse, East Ayrshire Council and the local Carers Centre developed a range of supports to address this.

A successful bid for funding by the Carers Centre to meet the needs of this particular group, through developing and extending existing provision to young carers was made to the Lloyds TSB Foundation (Partnership Drugs Initiative). The bid was supported by the council who matched the funding. As a result, young carers affected by substance misuse were able to access individual and group based support, training and education programmes, leisure and social activities, financial assistance, information and advice, and short breaks. Referral routes were agreed with social work and educational services.

Young people affected by parental substance misuse benefit from inclusion in mainstream services and specific services for young carers. They value the information and advice made available to them. The project ensures that young carers are supported by the relevant agency while also helping them to carry out their caring role effectively and appropriately to their age, needs and circumstances. The effectiveness of this service has been externally evaluated and the findings are positive. Young people report feeling better about themselves and that their sense of isolation and stigmatisation was reduced.

### **37. Edinburgh Young Carers**

**a) Older Young Carers:** Edinburgh Young Carers Project, offer a service of support to young carers from the age of 5-25. The project set up a specific group for 16-25 year olds, in response to an identified need to provide 'transitional' support to these young carers, who were balancing their caring roles with efforts to become more independent. Support to the 16+ group includes one-to-one support, intensive support, group work, a girls group, mentoring and residential trips.

The focus of the group is to empower the young people to make positive difference to their lives. Group members participate in various social activities where they can make friends and build on their confidence and self esteem. Their involvement in the group also enables them to build trusting relationships with staff.

The 16+ group also focuses on transitional issues, such as employability, housing, sexual health and well-being. To improve skills and confidence, training is provided on life skills, cooking, first aid and through the Duke of Edinburgh Award.

**b) Girls Group:** The need for a Girls' Group was identified as many of the 16+ girls had low levels of confidence and self esteem and some had issues with self-harm, anger and depression.

The Girls Group participate in various social activities, where they can make and develop friendships and build confidence and self-esteem in a safe and trusting environment. The Girls Group look at issues such as health, well-being and personal safety. Through Edinburgh Leisure they have participated in self-defence classes and in partnership with Caledonia Youth they have undertaken sexual health and relationship workshops.

The Girls Group is very much young person-centred and members are actively involved in all levels of the planning, organising and facilitating the group.

### **38. For Highland's Young Carers**

*For Highland's Young Carers* has worked with community partners in Highland to contribute to their Integrated Children's Services Plan (ICSP). As a result, the ICSP incorporates all the key aims and actions from the Highland Young Carers Strategy. It also makes strong links to the *Getting It Right For Every Child (GIRFEC)* well-being indicators, as follows:



.....to enable young carers to be included. We will provide information to professionals who work with children, young people or parents and provide accessible specialist information to young carers.

.....for young carers to be included. We will facilitate opportunities for young carers to support each other.

.....for young carers to be respected and responsible. We will train professionals who work with children, young people or parents about young carers' issues and needs.

.....for young carers to be safe. We will work with appropriate services to ensure mechanisms are in place to identify young carers and also children in vulnerable families who are likely to take on inappropriate caring roles in the future. We will provide opportunities for young carers to identify themselves and be aware of their rights.

.....for young carers to be safe. We will work with appropriate services to ensure mechanisms are in place to support family members who would otherwise rely on children taking on inappropriate caring roles.

.....for young carers to be achieving. We will ensure that young carers have opportunities to be assessed to establish any additional support needs and supported through periods of transition and vulnerability.

.....for young carers to be nurtured. We will continue to develop the availability of effective and structured respite opportunities for young carers in Highland.

..... for young carers to be healthy. We will further develop existing opportunities for mentoring/ counselling or one to one support for young carers when required.

### **39. LEAD Scotland and Aberdeen Foyer**

This is a joint project with young carers in North Aberdeenshire as part of the More Choices, More Chances strategy.

Many young carers are in families with low incomes and many young carers are socially isolated and lack a supportive peer network. In response, Lead Scotland organised a funded programme for young carers, which included activity and adventure sessions. These aimed to build the young carers' confidence, enhance their social skills and address feelings of anger and resentment through team building and individual challenge. The results were very positive and included progression to learning opportunities (in, for example, small animal care, making DVDs, re-engaging with school).

As a result of the successes further activity was arranged with another two groups of young carers. This wouldn't have been possible without the funding to pay for transport, as North Aberdeenshire is primarily a rural area with limited public transport.

The second group of young carers went on to undertake training in Peer Mentoring so they could support other Young Carers. Along with the training, they produced leaflets, using graphic software, to help others young carers understand that they need not be alone isolated and can have access to support from a mentor. The group also requested and received training to help them to cope with the challenges and strains of their role – suicide awareness, healthy eating, First Aid.

#### **40. NHS Borders - Young Carers Voice**

Using Carer Information Strategy funding, NHS Borders funded the development of Young Carers Voice, a consultation forum that brings young carers together to enable them to have a say on issues around the planning and delivery of services that may affect them.

Young Carers Voice helps to inform the Carers' Planning Group which has overall responsibility for monitoring all carers' strategies. It ensures that young carers are included in consultations and planning of service delivery, including young carers' services. Participants have all been very positive about this process and are keen to be involved again in future events.

#### **41. NHS Fife – Fife Young Carers**

NHS Fife's Carer Information Strategy Group have funded a young carers Information and Liaison Worker to raise awareness of young carers issues within schools, NHS staff, social workers and wider public, and to meet the training and information needs of young carers attending Fife Young Carers.

The Information and Liaison Worker has developed Fife Young Carers' own website, young carers' online forum and quarterly newsletter. She has developed a healthy eating resource and arranged "save a life" training for young carers from the British Red Cross. She has delivered awareness sessions on young carers to local secondary and primary schools, as well as to third sector organisations, guidance teams and the general public. A health and well-being event took place which promoted physical activity, healthy eating and lifestyles, including moving and handling techniques, in addition to providing information about a variety of local organisations and sources of help for young carers' families.

As a result, young carers have better access to information. They have participated in drama activities to improve self confidence and esteem and have better knowledge of healthy eating through work undertaken at support groups. Raised awareness has resulted in increased numbers of young carers being referred to Fife Young Carers.

## **42. The Princess Royal Trust for Carers – Mental Health Development Worker**

Young carers attending the Scottish Young Carers Festival in 2009 highlighted the need for improved help in understanding and dealing with mental health issues. In response, the Scottish Government has funded a young carers Mental Health Development Worker, who has been appointed by the Princess Royal Trust for Carers in Scotland.

The Development Worker will have the dual role of developing accessible information for young carers on mental health issues and advancing a range of measures to enhance young carers' own mental health and well-being.

This will be achieved by the Development Worker liaising with mental health agencies, advocacy services, befriending organisations, NHS Boards and local authorities to develop a network of support for referrals to young carers' services and from young carers' services to other external agencies as required.

The Development Worker will raise awareness of young carers' specific needs around mental health and well-being so that information being provided by mental health organisations and others, including NHS and local authority services is tailored to their needs.

## **43. The Princess Royal Trust for Carers – Young Carers Toolkit for Primary School Teachers**

The 2001 Census suggested that nearly 25% of identified young carers were of primary school age. As primary school children spend most of their school week with the same teacher, primary school teachers are very well placed to identify which of them may be young carers.

In response to feedback from the Scottish Young Carers' Festival, the Scottish Government has provided funding to the Princess Royal Trust for Carers to commission a toolkit to assist primary school staff to identify young carers. This recognises that these younger carers may be particularly vulnerable and may require more intensive support to achieve improved outcomes.

The toolkit will also highlight the importance of relevant information about a pupil's role as a young carer being communicated on at times of transition, which can occur at any point in a child or young person's education.

Linked to the development of the toolkit to identify young carers in primary schools, the Scottish Government has also provided funding for the Princess Royal Trust for Carers to commission a media project. This will create a nationally known character which younger children will come to identify with as a young carer. A media campaign will promote this young carer "mascot", which younger carers will be able to identify with and which will help remove the stigma of being a young carer and make them feel less isolated. Primary school teachers will be able to use this character and supporting materials to highlight caring relationships, to encourage young carers to self-identify and to promote the support that is available.

#### **44. Skye and Lochalsh Young Carers Project**

**a) GP Project:** Skye and Lochalsh Young Carers' Project have worked with local GP practices to raise practitioners' awareness of the issues affecting young carers. As a result, GP practices are now flagging up young carers on their patient records, with the Young Carers Project obtaining parental consent each year.

Young carers report that this has resulted in GPs now spending more time with them and they are more likely to look beyond physical ailments and to provide emotional support, as well as information and advice. Young carers can now request double appointments as necessary. This approach also alerts locum doctors to particular issues impacting on young carers' health and well-being.

**b) School Based Support:** Both Plockton and Portree High Schools have been supported by Skye and Lochalsh Young Carers Project to develop a "Young Carers' Policy" which initiates a number of actions designed to identify and support young carers. The policy: gives special responsibility for young carers to two members of staff; ensures that awareness of young carers' issues is raised in assemblies, Personal and Social Education classes, through leaflets and the schools' website; alerts subject teachers to young carers in class; and, it promotes information about the support available through the Young Carers' Project

As a result of input to assemblies at Portree High School, the numbers of young carers coming forward for support rose from 30 in March 2009 to 46 in March 2010.

In addition, the Portree High School and Plockton High School Young Carers' Policy makes specific provision to address the demands that young carers face and which can impact on their school attendance, conduct and attainment.

These include:

- sensitivity to the needs of parents with disabilities
- access to bus passes to facilitate extra curricular activities
- allowing young carers to keep mobile phones on in class
- ensuring that detention does not clash with caring responsibilities
- referral to the young carers project when respite care is needed
- making provision for young carers arising late at school
- providing support for learning and access to facilities when available
- the introduction of 'out of class cards' and 'chill-out' room at times of high anxiety
- extensions to homework deadlines
- appropriate internal exclusion arrangements
- identifying young carers in GIRFEC plans
- recognising and celebrating young carers' achievements
- involving young carers in training on disability and caring issues

**c) Police and Fire Services:** Skye and Lochalsh Young Carers' Project have worked with the Police and Fire Services to raise their awareness of young carers and the issues that affect them. This has enabled them to identify young carers in their day to day work and to consider the potential that young people may be carers

in the homes they visit. As a result young carers have expressed more positive views of the emergency services and report that they are much more confident about identifying themselves as young carers.

Work with the police also raised young carers' awareness on a range of legal and personal safety issues. This has helped reduce inappropriate caring roles and risks and made young carers and their parents more aware of the guidance about being left alone at home.

The work with the fire service has resulted in a number of families agreeing to fire safety home visits. Also homes are now being flagged so that additional support would be provided, if required. Information cards were created to hang inside the access door, to provide fire crews with information on emergency medication, additional supports needs, numbers in the household and other relevant information.

#### **45. Stirling Young Carers' Schools Project**

The project developed a range of measures to build support for young carers in Schools. Each of the schools involved was provided with a resource pack, signed up to a Young Carers' Charter, appointed a member of staff to be their school's young carers' co-ordinator in each school and implemented staff training on young carer awareness.

Support continues to be provided by the young carers' co-ordinators who have the responsibility and knowledge to provide support to young carers in school, or to refer them on to the local Young Carers' Project.

## Part 3: Carers' Stories

### 1. Paul: Double carer for wife with multiple sclerosis (MS) and daughter with cerebral palsy

My name is Paul and I have been a carer for 27 years. My wife has been a multiple sclerosis sufferer for the last 25 years and has spent the last 19 years in a wheelchair. We have two daughters. Unfortunately our youngest one was starved of oxygen at birth and is cerebral palsied. As a result, she has been totally dependant on other people for all her needs and so, for most of the last 27 years I have been a double carer.

My wife's MS progressed slowly at first and then following the birth of our second daughter moved quite rapidly. It was clear from the start that we needed to do some long term planning. First step - get a house that can be adapted for the family's future needs. This was probably the most important decision we ever made. You try living in a house with two wheelchair users that isn't suitable - not a good idea.

As my wife's condition deteriorated my caring role increased – I was still managing (just ) to hold down my job. However as time went on the cumulative effects of stress and, interrupted sleep caused my body to rebel in the form of a severe case of hives and I woke up in hospital the next day wondering who on earth was looking after my wife and children. Luckily my parents had relocated from England to help me and were on hand to help.

At this point I realised that I was not actually superman and that to continue in the caring role I would have to get some help. Via a combination of support from the local social work department, health services and the Independent Living Fund and using 'Telecare' we managed to create a comprehensive care package where I basically do the care for my wife and daughter between 5.00 pm and 7.45 am each day.

I get 32 days/nights respite for each of them and find that my main supports come from other family members, parents/carers and the local carers organisation - Carers of West Lothian. I am actually quite proud to be a carer- it's not something I would have chosen to do but my philosophy has always been – if you are going to do something – do it well. Our family unit is strong and loving –the result of having weathered many a storm that could have sunk us. There have been substantial financial, social and health impacts along the way but at the same time other opportunities have opened up. Via the world of disability we have met some incredibly strong and supportive people whom I am now proud to call really close friends.

The supports that have been put in place enable me to carry out my role as a carer but equally important enable me to live a fulfilling life as well. I am able to do the kind of things that I want to do (which in my case includes a lot of voluntary work) and at the same time make a positive contribution to society.

Having been a carer for so long I have met many people in the same kind of situation, and one of the things I have picked up on is the reluctance of people to

recognise themselves as 'carers' - they are, wives, fathers, husbands, children first and they don't want to label themselves with another title. It is this perception that we need to challenge - **we are a good thing**, a fundamental building block of society and through our efforts, we save the public purse **billions** of pounds.

Because the caring role has long been one that attracts low pay in the private and public sector with minimum qualification requirements it has engendered a subconscious reaction that has low esteem. This is where government has a critical role to play, both at local and central levels. We need to better identify, inform and support in financial and through the co-ordinated use of existing resources the unpaid carers in our society.

There is a great battle going on (though they will never admit it publicly) between central government the local authorities and the health boards/trusts as to who does what and who gets the money for providing services. As a carer **I don't care who provides our service - what I care about is the quality and reliability of the service provided.**

My message to other people reading this is – if you are a carer-recognise yourself as such- join your local carers organisation. If you are a male reader you will find that message much harder to accept than your female counterpart because you like me will want to take all the responsibility and the physical duties on yourself, convinced that **you can** manage it and that to share the burden with someone else would be a display of weakness.

The truth is, as I found to my regret, your body will only take so much. It is much better to retain that central management, caring, coping role by seeking out supports before the crisis situation arises - they are out there if you look hard enough, but they certainly won't fall into your lap! - once you get them you will find that the caring role need not be as hard as it could be, you will be able to do it better and for a much longer time and you will be healthier and less stressed to boot, but, and it's a big but, your privacy goes out the window, say goodbye to it quickly and, you know what? In the end - it's actually a small price to pay.

As a result of my voluntary work I have been fortunate to gain an insight into the workings of my local authority and health board so if you are a service provider/commissioner my message is simple - in the vast majority of cases if we can identify carers at an early stage and put in small support packages, this strategy will pay massive dividends further down the line - 'Invest to save' and for goodness sake strip away your expensive bureaucracies and embrace partnership working for all our sakes.

The distinctions between health and social services is still ingrained in staff at the service delivery level and the budget protectionism at all levels of management is hindering real progress towards the vision of joined up/seamless services that you purport to achieve.



## **2. Sally: Carer for adult son with verbal dyspraxia and learning difficulties**

My name is Sally and I care for my son Mark who is now 21 and has verbal dyspraxia and learning difficulties. I have been battling with authorities since Mark was two years of age to ensure he receives the services he is entitled to, but that is another story.

This is a very positive, true story about the service we have received from our local area co-ordinator, Tricia. Completely out of the blue Tricia phoned me one day back in 2006, introducing herself as a local area co-ordinator, a new post created by the council and that she was there to work with and help families who had children with learning disabilities. She arranged to come and visit me and discuss Mark's needs. I didn't have high hopes that this would amount to much, it seemed to me she had a somewhat meaningless job title and was coming for a coffee and chat before sympathising and explaining the resources just weren't there. Unfortunately experience has made me somewhat cynical at times.

Anyway, Tricia came cheerful and full of enthusiasm. We discussed where Mark was which was the transition from special school to a supported college course, entailing moving into halls of residence. Mark and I had visited the college and he had been on a two day taster session resulting in Mark being excited about leaving school and going to college as 'normal' young adults do. The problem I was having at that time was obtaining a social worker for Mark. He needed a care plan in order to access funding for his transition and the council repeatedly told me they didn't have a social worker spare. It was through Tricia's intervention that Mark was allocated a social worker and her guidance that saw that the funding etc was put in place (just in time) for Mark to start his transition to college.

She also arranged for Mark to have weekly support sessions with a male member of staff before leaving home. There had been some issues around Mark's behaviour and as I am a single parent Mark is lacking a male adult figure in his life.

Tricia, through her work with other families has arranged for some of us mums to get together every so often. We find these evenings great, it gives us a chance to meet up and discuss our different experiences and give each other mutual support. Tricia is there on tap giving advice and encouragement. She has also got us to arrange two 'futures meetings' whereby we invited different agencies, including housing and welfare rights, to an informal evening where parents can come to find out what these agencies have to offer us. Often parents do not know what help is out there or what some of these agencies do.

Tricia kept in touch with us whilst Mark was at college and made sure everything was going smoothly. When Mark finished his original course she was there whilst he applied for a regular course and was able to keep me up to date with the progress of the funding for this. As he completed the first year of this second course I was concerned that he may not be capable to continue with the second year and wanted to explore his future options and also make sure Mark had the opportunity to express what he wanted to do and that every effort was made to achieve what he wanted. Tricia suggested a person centred planning meeting and organised this. This

enabled Mark, in the comfort of his own surroundings, to make his desires known and tell us what he definitely didn't want.

It transpired that although he wanted to continue at college this was not going to be possible so he decided he wanted to stay in the city, have his own flat and find work. Tricia wrote up the notes from the meeting and set out a 'to do list' giving leads as to who could help achieve Mark's wishes. She also arranged for me to attend a housing options workshop. This was very useful as I was able to meet housing professionals from both the public and charitable sector, support sector workers and other parents to share ideas and issues. I found it enlightening that these people were 'thinking outside the box' and that disabled people's real needs were being taken seriously rather than having to fit within a rigid criteria. It gave me confidence when filling in housing application forms with Tricia's help. I was also able to give feedback to the other mums when we met up.

At the housing workshop I made contact with the charity ENABLE who are now in the process of helping find a work placement for Mark. They also told me about their trust making service and again with Tricia's help I invited Sophie to come and speak to local parents about this valuable service that most of us had not thought about. Mark has now made the transition from college to his own flat and is waiting to start a work placement. The transition has not gone entirely to plan, the promised social work support has not been forthcoming and Tricia has helped me make a formal complaint to both the authority he has moved from and the authority he is now living in. She is still supporting us.

I have found Tricia's support invaluable. She is able to cut across local authority departments and has a thorough knowledge of all the services available. I have found she is able to anticipate what help and support we need and come up with solutions and ideas that we are not aware of. She has always made herself available to us and been cheerful and positive. Since Tricia's intervention into our lives the constant 'battle' and my frustration at trying to gain the services that my son is entitled to has been lessened, I often find it hard to believe that Tricia is employed by the local council!

Due to my positive experience of the service provided by Tricia as a local area co-ordinator I have been willing to give my time to help improve services for disabled people. I am now a member of the locality forum who are looking at the options for the re-design of the local learning disability service and the local area co-ordination national reference group. Being aware of the good practice that can be given and received I am anxious that this becomes the norm and the service of local area co-ordinators is made available nationwide to all families where learning disability is present.

### **3. Parent Carer: Carer for young son with Asperger's and young son who is autistic**

I care for my two sons, James who is thirteen, he has Asperger's and Ryan is eight, he is Autistic. My mother also has many health issues and I share her care with other members of my family. I always knew there was something a bit different about James. When I took him to our GP I was told that I was an over protective mother. He went to a mainstream school in primary one, in primary two and three he attended a language unit due to problems with his speech. He talked really quickly. He returned to mainstream school in primary four. I encountered one problem after another there. James is a highly emotional child. Staff couldn't cope with him, often he would be sent out to the corridor crying. I got the impression they didn't want him there. I decided to change to another school.

The staff there worked really well with James, he was a lot happier, therefore so was I. Ryan went to nursery, he didn't speak. The nursery staff were excellent. It took them a year to make progress with him from sitting in a corner on his own to participating in activities with the other children. They even managed to get him to play a part in the Christmas play. He was diagnosed when he was four. As a result of the experience from Ryan's situation, James benefited. He was diagnosed shortly afterwards. Although there are similarities between the boys there are also extreme differences. I have to make five different sets of plans before I do anything. My children have to be supervised at all times. Ryan can't be left in a room on his own. He tried to cook me breakfast for mother's day and before I knew what he was doing the flames were leaping out of the frying pan. On another occasion, at a birthday party, he used a kitchen knife to burst balloons. He has no sense of danger. The boys attend various clubs. They have to be able to function in two worlds, with children who are the same as they are, and also with other children.

The thing with autism is, there's no treatment for it. When you are given the diagnosis, although it is a relief, medically there's nothing doctors can do. Often if people don't see a physical disability it doesn't exist. What has helped me most is speaking to other parents. I have made many friends through the children. We share experiences and give each other advice on how to deal with things. I do manage to have a social life but find it easier to go out with other parent carer friends as they understand when I have to let them down and vice versa. Parents are sometimes wary of telling a social worker about how they feel but will be happy to tell another parent.

I am involved in the ICCAN Group (Information for Carers of Children with Additional Needs). It feels great being able to help other parents in the same situation and it is good for my self esteem. I also attend the Local Carers Network where I can speak to other carers and they can also learn from me. I have picked up some useful information there, in particular legal issues regarding guardianship.

Over the years I have learned to follow my own instincts, decide what I want for my children and fight for it. At times I likened myself to Coronation Street's battleaxe Ena Sharples! This year, James was offered a place at High School. There was only one place available and he got it. I couldn't believe it, for once we were offered something without having to fight for it. My life is unpredictable but never boring. I try

not to expect too much or look for every milestone in the boys' lives. I worry about their future when they become adults because that's a whole new ball game.

#### **4. Fathers: A selection of fathers' quotes**

- a) Before I became involved with the fathers group I felt I was on my own. It was nice to see that others were in the same boat and that there were people in the same situation as I was.
- b) I have people supporting me and providing me with information who understand things from a man's point of view". I don't have to put a brave face on everything, as nine times out of ten somebody in the group had been where I was and helped me to solve the situation.
- c) I used to sit at home and feel sorry for myself and have no doubts I was suffering from depression due in part to my lack of mobility. I was told about the group by a friend and now I look forward to the meetings and activities as the other guys are very helpful and ensure that my son takes part in everything. The monthly meetings allow us all an insight into the problems individual families face, and we work together to find solutions, its like you are part of a big family. That for me is important as I wouldn't just allow anyone to look after my son.
- d) The activities provided by the Fathers Group are so well organised. The support the other fathers give me is amazing and if it weren't for them my son and I wouldn't be able to attend, due to the problems I have with my own health.
- e) I am very much a family man and don't go out much. The fathers group allows me to socialise with people who understand the challenges I face on a daily basis. The activities allow my son to meet other young people in a safe and controlled environment.
- f) Before I joined the Fathers Group I sat in the house and felt sorry for myself. My involvement with the group has allowed me to attend activities and develop and appreciate the relationship I have with my child, it also gives the wife a break and allows her some time to herself.
- g) The fathers group provides me and my child with activities and interests I would never normally take part in. Having a child with a disability tends to force the family into isolation as you can't do the normal family things due to the amount of support needed. That Fathers Group provides me with individual support as well as support for my partner and our children.
- h) The Fathers Group gives me support and I feel I can say anything without anyone taking offence or judging me or my family.
- i) The Fathers Group provides a safe environment where I can spend quality time with not just my disabled child but my whole family. It also allows my wife to have some time to herself and do things with my daughter which she can't normally do, due to the fact a lot of her time is taken up looking after our son.

- j) The activities the Fathers Group put on are safe and at a level to suit my child's disability, they are so varied that there is always something to suit everyone. We have done things together I know I would never have tried on my own.
- k) The monthly meetings have been a great benefit to me as you can bet your life that someone has had the same or a similar problem you are having, and someone is always willing to give you the benefit of their experience and offer advice and guidance.
- l) The Fathers Group has helped me by being able to talk to other dads; this eases the frustration and anxiety I would normally bottle up, which usually resulted in me falling out with the wife.
- m) My eldest child felt left out at times due the time my wife and I spend with their sibling. The Fathers Group helped as it gave our family the opportunity to do things that "normal" families do. The activities are varied and it allows me and the wife to relax as we know there are like minded people looking out for our kids. There isn't another group locally that provides this type of activity where the whole family can take part and I feel the biggest benefit is that this has resulted in my elder child being less resentful of their younger sibling.
- n) Being part of the group I can let my guard down. I don't have to put on a brave face, as the group understands things from a man's point of view. You can bet your life that nine times out of ten someone in the group has been where you are at some point, and has a solution or knows how to at least look for one.
- o) Being a member of the fathers group made me realise that I was as important as my partner when it came to caring for our child. Hearing what other fathers said made me realise that as the father of a child with a disability I was being left out in a lot of the decisions made. The group made me more aware of this, and although I didn't attend all the professional meetings I was more aware of them and would make suggestions I would previously have felt was not my right. This helped the relationship with me and my partner as by taking an interest she says that she now feels she isn't on her own.
- p) I receive regular information about future events as well as hearing about past ones. I like the fact there is no pressure and it doesn't seem to matter if I don't attend every event.
- q) I admit that the first meeting I attended in the early years was not enjoyable, we sat round in a circle and it was like one of those self help groups you see on television. I felt uncomfortable and had decided that I wouldn't be back. The guy from Quarriers phoned me after the meeting and I told him how I felt. The next meeting I attended was completely different and so relaxed that I have been a member for over five years. I think the strength of the group is that although it is well structured, it steers itself, and is flexible enough to change and meet the needs of the guys and the families.

- r) I think the big thing for me was that until I joined the Fathers Group I looked for problems. From hearing what others had overcome it seemed to rub off on me and instead of looking for problems I found myself looking for solutions, not just for my self but for the others.
- s) The Fathers Group made me realise that I was far from being in the worst situation and stopped me feeling sorry for myself. I learned from others problems and how they overcame them.
- t) I was given advice and guidance which I have no doubt I may have got at some point but probably after going round the houses. The group saved me a lot of pain.
- u) The father's group provides me with individual support as well as providing activities tailored to suit the needs of my family. The group's strength is in its numbers as you can book venues and events to meet the needs of children with a disability. This is not possible for individuals and other youth groups due to the cost.



## **5. Eileen: Carer for mother who is frail and who has a combination of medical needs**

My name is Eileen, I am 52 years old and have been caring for my mum, who is frail and has a combination of medical needs, for about five years. I moved back to Scotland from America in 2006 to be nearer my family. At first I had my own flat and a job but I was aware that my mum's health was deteriorating. Eventually I gave up my flat and moved in with mum. My employment contract was coming to an end and I knew I would find it difficult to continue to work as mum needed more care. She had frequent admissions to hospital and I was finding balancing that with work more and more difficult so I gave up work to concentrate on looking after her. Over time I became more isolated. I'd stop making arrangements with friends as I'd be frightened of letting them down. I felt that I was unreliable and I hated that.

After a while other members of my family began to notice that I was really stressed, although I would not acknowledge it myself. I felt that I couldn't talk about how I was feeling as it would look as if I wasn't coping. Feeling that way made me feel guilty, I told myself that she was my mum and that I should be able to cope. When people asked how I was I would tell them that I was fine although inside I knew I wasn't fine. I felt stressed and exhausted. My sister constantly told me that I was a carer and that I should ask for help and for a long time I ignored her. I didn't think of myself as a carer and despite many visits to the GP and workers coming to see mum at home, no-one had ever spoken to me about getting support for myself, so that reinforced my view that I couldn't get help. Finally my sister made an appointment at the local carers' centre for me. I went along and met with a carer support worker and finally began to realise that I was a carer and that I could get support and help for me, although I still did feel a sense of guilt.

The support worker told me about carers assessments and suggested that we complete one. Over time we talked about all aspects of how caring had affected me. I began to get regular support from the support worker. At first it was mostly emotional support which I needed most as I still found it hard to acknowledge that all this support was available just for me. I also realised that the carers' centre offered much more than just financial assistance which was what I thought at first. Eventually as I began to get some confidence back and with a bit of gentle persuasion from the support worker I started to make use of the other services which the carers' centre had to offer. At first, the thought of being amongst other people was a bit intimidating but as soon as I met other carers and started to hear their stories I realised that there were many people who were going through the same thing.

I took advantage of some of the carers training which was on offer - Moving and Assisting, Complementary Therapy Workshops, Continence Awareness and Looking after your Money. The training gave me practical tips which help me to care for my mum. It's also good to meet other carers and share ideas. It helps you to feel better and less alone. I attended the centre for aromatherapy sessions which I really enjoyed and I then began to get more involved in other things which the centre offers. I took part in their "Staying Well" support group and I joined the craft group and the reading group as well as some of the social events. I love the reading group, we have great discussions and I really feel as if I can help other carers now by sharing my experiences of how I cope. The support worker helped me get money to

purchase a special recliner chair for mum and money to get me a short break. I used the money to go away for a weekend and I felt truly pampered.

They also helped me with things that can help me care for mum. They helped me get a bathing assessment, a new wheelchair and I now get more respite which gives me the breaks that I really need.

When I look back, I don't know how I was coping and I don't know where I'd be if I hadn't got help. Although I know that I still suffer from stress, I do feel better emotionally. I've become involved in volunteering and I helped the carers' centre work on a "Looking After your Money" booklet for carers, I enjoy knowing that I've helped someone else. I've also stopped smoking!

I still face challenges with mum, her memory is fading and that can be very difficult to deal with but I think I'm stronger than I was and I am coping better than I did. Knowing that the carers' centre is there for me has been a lifesaver.

## **6. Carers: Carer aged 85 for adult son (aged 43) who is autistic**

I care for my son Tom who is Autistic. Tom is my fourth and youngest child. When he was five or six I noticed that something wasn't quite right. The headmaster at his school, suggested that Tom should see a psychiatrist. The psychiatrist reported that he was just a spoiled boy who had been over indulged by his parents and grandmother. I imagine that would be a regular reaction then as Autism wasn't widely recognised. Even now people are not aware of it and I wish they could be better educated. My son doesn't like crowds and when in that situation he puts his jacket over his head. People stop and stare. I've calmed down a lot over the years but it used to make me angry to the point of challenging those who stared or laughed at him.

Tom has a tendency to fidget. One day when we were in a card shop, a member of staff who was watching Tom's actions approached us and accused him of shoplifting. On another occasion I was in Glasgow City Centre with him when he had to visit the toilet. I waited for him outside for quite some time but he didn't re-appear. I discovered that there was a back door he had used. I managed to find him but one of my fears is that he will get lost. Tom was put through numerous tests but it wasn't until he was in his twenties that he was diagnosed.

A specialist came to our home and within five minutes of watching Tom put together a jigsaw he was able to tell me that he was Autistic. I had two children with my first husband. When he died, I had to go out to work in order to make ends meet. I worked in a factory making wires for switch gear. I later re-married and had my other two children. My mother came to stay with us for what I thought would be a couple of years. She was with us for almost 30 years, she died aged 99. I am a member of the Women's Rural Institute. I played the piano for the concert party and I was one half of a Laurel and Hardy double act. For 20 years we went round nursing homes entertaining the residents.

When my second husband died I had to learn to drive because although Tom is physically fit (he won a medal at the Special Olympics) it is dangerous for us when trying to cross a busy road. He is strong and I can't hold him back so it's better to go to the library, doctor etc by car. I got my driving licence when I was 75 but I had to fight with the Department of Social Security for ten years to get a car. I am now 85. Tom is 43 and I still have to fight for the things we need. One item I find invaluable is the "Communication Passport" and I am very grateful to the ladies from Kirklands Hospital who came up with the idea. It's a small book which contains information about Tom's routines, his likes and dislikes and other personal information. He takes this with him when he goes to Hansel Village for respite. I think this is something that many carers of people with communication difficulties would find helpful.

The good thing about the Carers Network's monthly meetings is the sharing of information. I have learned that there are many different aspects of caring. It's not an easy life but I have strong faith and feel that my life is mapped out for me.

## **7. Karen: Carer for adult son with obsessive compulsive disorder and Asperger's Syndrome and for partner who had a brain haemorrhage and also has epilepsy**

My name is Karen, I care for my son and my partner. My son is nearly 25 and has obsessive compulsive disorder and was also diagnosed as having Aspergers Syndrome which is a form of Autism. My partner has a brain haemorrhage and epilepsy. I also have Agoraphobia and Hidradentis Suppurativa.

Before I started getting help I was near to having my second breakdown, but one of my friends suggested that I contact the housing department as I was having problems with the neighbours at the time. I did this and was allocated a housing support worker. Through this person helping me, it had a ripple effect. They contacted the Dundee Carers Centre and from then on I had someone listening to me for the first time. I was not aware there could be help out there for all of us. Bit by bit things are changing for us all. We even managed to get a diagnosis from the doctor for my son, after about a year of being told there was nothing wrong with him. (I always knew there was something not quite right with him).

We finally managed to get the mental health team for the help and support he needs, which is ongoing and he is making steady progress. He is now at college full time and doing well and we now know what we are doing and dealing with.

My partner has also made progress. He now has a befriender which gives him something to do. He looks forward to this every week and we are trying to get my partner motivated and build a bit more structure into his life.

While I am a service user and a carer, I also have a befriender myself which helps me to get out and about. It is my bolt hole and it gives me respite from my caring role, as I have felt isolated for a very long time. I am enjoying the new world around me now. I also have help from Crossroads with my own healthcare issues, because before the Dundee Carers Centre got involved I had non existence help with getting to doctors and hospital appointments etc.

Although we have not got everything sorted out we are getting there. For each of us every step we take is an improvement and a better quality of life.

Where there was despair and dejection there is now hope and optimism and a better future for us all. We are on the road to recovery thanks to all at the Dundee Carers Centre.

## **8. Louise: Carer for adult son (25) who has severe mental health problems**

My name is Karen and I am a carer. I care for my son who has a severe mental health problem. Of course, for a long time I did not know I was a carer. As far as I was concerned I was just a mum trying to do the best I could to look after my son. He is 25 years old now and first became unwell when he was about 16 years old. Over the years he has had various diagnoses such as schizophrenia, bi polar disorder and obsessive compulsive disorder. Recently he has had a serious physical illness which remained undiagnosed for several years due to professionals maintaining his symptoms were related to his mental health difficulties. This was despite my underlying gut feeling that something was physically wrong with my son but no one listened to me.

I too have mental health problems and am therefore a service user but it is as a carer that I first got involved with the forum just over a year ago and I am passionate about mental health carers' voices being heard!

Before support from GAMH Carers Support Project:

- I felt isolated and lost
- No one was listening to me
- Life was 'Hell' for myself and my son
- Both my son and myself were called 'psycho' or 'schizo'
- My role as a carer had a detrimental effect on my own mental health

I was finally referred to GAMH Carers Support Project where staff specifically give support to mental health carers. This is where I feel my story of recovery began.

I was given support to:

- Offload my feelings of fear, anxiety and helplessness
- Know my rights as a parent and a carer
- Effectively communicate with professional staff within psychiatric and social work services
- To access an assessment of my own needs as a carer
- Insist on being involved in my son's treatment and care as this was also what he wanted
- Attend a mental health carers support group which made me realise I was not alone and we supported each other

After some time, as I gained confidence, I felt that I wanted to do more to raise awareness of mental health carers' situations/issues and I was introduced to a local Service Users and Carers Forum.

I feel the benefits of the forum for me are:

- Sharing experiences, knowing others understand
- Getting carers and service users' voices heard in the right places – planners and decision makers. 'Bosses' are more willing to listen if we all work together
- Service users and carers sharing and learning from each other
- Getting up to date information about new developments

- Getting the support and confidence to speak up at other events/ conferences/ forums

Looking back over the past three years I can see how my confidence has increased. I never expected to be able to stand up in front of people and speak but this is exactly what I did at the launch of the new forum. This is all part of my continuous journey of recovery as a service user and a carer.

I have been involved as a befriender in a befriending project for Mental Health Carers and I saw this as part of my own respite and contributing to reducing other carers social isolation as I know what it feels like “not to be noticed”.

I also attend and contribute at the Glasgow Citywide Carers Forum Mental Health in order to highlight concerns that affect carers of people with mental health problems and influence the policy makers of Mental Health Services in Glasgow.

I don't know what the future holds but I know that I want to continue to raise awareness locally and centrally about the importance of mental health carers being recognised and respected as equal partners.

## **9. Carer: Carer for partner who has obsessive compulsive disorder**

I care for my partner, who nine years ago was finally diagnosed with obsessive compulsive disorder after living and struggling with it for all his adult life. Both he and I knew very little about this disorder, although he was only too aware of what it was like for him and the havoc it had already wreaked in his life.

Typically, we were both left to struggle on alone, post diagnosis. Gradually a care team evolved – over several years. They didn't involve me and I didn't feel it was anything to do with me. Meanwhile the impact of the OCD on our lives and relationship was profound. Five years on, and my partner's CPN (since moved out of region and been replaced) mentioned to me that NSF Scotland in Dumfries and Galloway would be a good place to look for support for both of us. He explained that there was a carer's support worker. This was the first time the word 'carer' had been attributed to me and initially it didn't seem relevant. It felt like an indulgence. I was his partner who supported him, 'managed' many aspects of his life for him, and struggled with the effects of his illness. A carer was someone who pushed wheel chairs and helped wash and dress.

Several months later I contacted the carer's support worker and we met at the NSF Scotland centre in Annan. At this stage I was not acknowledging the implications for myself of my partner's illness, and of my evolving role as carer. Consequently I still felt this meeting was irrelevant and, in fact, a case of me wasting the time of NSF Scotland. I hasten to add that this was entirely my perception, and nothing to do with the support worker! It was simply a case of my mind and ears were not yet open to the whole situation that I was in.

Maybe a year later, as things grew increasingly more difficult and my despair grew, I again contacted NSF Scotland for support. A new support worker was by then in post (a manager filling the role on a temporary basis) and this time I was ready to 'spill the beans' about the whole mess that my home life had become.

The support worker treated me with great sensitivity and professionalism, and really validated my carer's role for me. Over several sessions at the centre in Annan I really began to see that it wasn't my imagination, I wasn't over reacting, and I was still a person within the situation who had my own needs. My needs, at that time, were quite simply these one to one sessions that gave me space, a voice, and offered me advice.

The carer groups were mentioned to me but at this stage of my internal chaos I was not comfortable to 'go public' with my situation. It was more about beginning to accept the situation for myself.

These sessions got me through a very dark phase and as a result of the time with the support worker I began to feel more empowered within my home rather than a helpless victim of circumstances.

Another year on, and a new carer's support worker in post, I again hit a dark patch. A couple of one to one sessions again helped me to see light at the end of the tunnel, and this time when the carer groups were suggested, I felt that it would be a



good thing to get involved with. At this stage it was less for the social side and more to do with the many really relevant guest speakers that are always invited along.

So, I started to going to the monthly group meetings in Dumfries, and quickly realised that I was not alone in my chaos. I became able to laugh about it, rant about it, share it. The Dumfries and Galloway NSF Scotland carer's support is now my first 'port of call' when I need information, advice or help through another dark patch. One e-mail or phone call is all it takes to get help. There is nowhere else to get this 'one-stop-shop' service.

A great example of how it all works for me is my carer's assessment. I was totally unaware that such a thing existed, but as I sat and listened to more and more anecdotes and guest speakers at the carer group meetings making reference to these mythical things, and being encouraged by the support worker to pursue one for myself, I began to feel that, yes, it was something that I should pursue.

Of course, it wasn't that simple! It was only through the involvement and persistence of the carer support worker, and her involving further professionals, that I finally had a successful outcome.

More examples of how this NSF Scotland 'one-stop-shop' works for me are the contacts that I have made via the support worker. Carer stress management training days, a place on the 2010 Prospect weekend, a social worker of my own are just some of these examples.

## **10. Parent Carer: Carer for son who has schizophrenia**

Our nightmare began in 1980. My son was at high school when his behaviour began to change, through his drawings he showed a certain amount of hatred for his dad. I went to our GP and he felt the behaviour was related to his age and it was just a stage he was going through, which I accepted. However, his behaviour did not improve. In fact, it got steadily worse. I remember the last holiday we went on as a family - I was in the laundry room when I heard someone shouting and using the most disgusting language. When I left I realised that the shouting was coming from our caravan: it was my son shouting at my husband. We felt so embarrassed and sickened that we packed up and went straight home.

Eventually, our GP made a psychiatrist's appointment and we were referred to the social work department. The social worker said it was me who had something wrong and not my son. I attended the psychiatrist's appointments myself as my son refused to go. The psychiatrist suggested that the whole family spend a week together in the family unit at a psychiatric hospital: my son would go on his own for one week and the rest of the family would join him for the second week. My husband had a responsible job in a factory and my daughter was at college, which made it difficult to take time off but we all agreed to go as we would have done anything to help my son. We took him to hospital and he was shown round by one of the nurses. After being shown around he said that he didn't want to stay and as he couldn't be forced, we all returned home. I thought that he had blown his chance for help. We struggled on, on our own, and things just got steadily worse.

We moved to a bigger house, then as well as coping with my son's illness my husband was made redundant and the cottage we were moving into needed extensive renovations. My husband eventually got a new job, and my son started to become violent towards me. He would demand money and take it out of my purse, demanding more and more as he could never get enough. The violence was terrible: he would grab me round the throat and suddenly stop and apologise; he made holes in the walls and doors of the house; and the language he used towards me was disgusting. I was too frightened to tell the GP about this as I thought that he would be put into prison. To make matters worse he lost the few nice friends he had and, anyone being better than no one, he made friends with two nasty lads. I spent all my time looking for him. It got to the point where I was living in fear of my own son. I would hide from him in the garden or walk around the streets in my slippers until my husband came home. My husband also began to get abuse and we got to the point where we were locking our bedroom door at night. During this time we couldn't have felt lower. It was worse than any nightmare and although I loved my son, I also felt like I hated him so much.

After five years, things came to a head one night. My son was running around outside the house berserk: he was knocking on a local girl's door and she phoned the police, I also phoned the police and it was the doctor who phoned the hospital. My husband and I were both in tears: we imagined that he would be put in a straight jacket. He was taken away in an ambulance. My poor husband broke down at court as my son was being sectioned. He was told to pull himself together.

My son was in hospital for three months and during that time we visited him every day as well as running our business. However, we were asked to stay away for a while as we were upsetting him too much. We stayed away for three weeks, phoning

twice a day. We were asked endless questions by doctors and were given no explanations as to what was wrong. However, we knew that our son was in the best place and the staff were very kind. Later, we would visit him regularly, taking him out for runs and we would take some of the other patients with us if we went for a coffee to the cafe.

Eventually he was given a diagnosis of schizophrenia. We were devastated: it was like a death sentence. It felt as if we were grieving and I suppose we are still grieving inwardly. It has taken a long time for the correct combination of medication to be found with lots more downs along the way. There has been a massive change in my son since he's been on medication: he is a pleasure to be around now; we are not ashamed to take him out; he has a fantastic sense of humour; and is very friendly. He lives in supported accommodation and comes home to visit us every Friday and returns to his flat on the Monday.

I would like to urge other carers to get support for themselves (though it was years before I realised I was a "carer"). Never be discouraged or disheartened. If you're determined and look ahead, there is help and plenty of information out there. I have found that the National Schizophrenia Fellowship (Scotland) has been a great support and I would urge others to pluck up the courage to go to a carers' group.

Getting in touch with Fife Families Support Project was my lifeline. What I found really wonderful were the home visits. My husband and I were able to relax and talk to the carer's officer about what we were going through. He was also a valuable source of information.

Although it took me a while to pluck up the courage to go to a support group I am now at my happiest when attending the local meetings. We have become very close and special friends. There is such understanding, such a close bond. This is all part of my life now.

## **11. Parent Carer: Carer for daughter with border line personality disorder**

I am 49 years old, I have two lovely adult children and am happily married. My husband and I have worked hard all our lives and tried to bring up our kids in a loving and nurturing environment, where they were loved and respected for the individuals that they were and encouraged to love, respect and embrace their own individuality as well as others. Like most families, our kids were our priority and we took great pleasure in watching them grow from toddlers to teenagers.

Nine years ago our lives took a drastic change. A change we could never have foreseen. A change that would rock our whole family foundation to the very core. We entered into the world of 'mental health' and since then have we been on a roller coaster.

Looking back over the nine years, had we all been offered the support needed, things could have been so different. Had our daughter been 'listened' to properly, things would have been so different. Had we been listened to properly how different the last nine years would have been.

I could list pages and pages of bad practice and ignorance, that we have encountered, along with so many other users/carers within the NHS Mental Health System. However, like so many others I realise that to do so creates negative energy and could have a direct impact on the care my adult daughter may receive in the future, and it may close more doors than it opens.

For many years, in fact each time our daughter had been hospitalised, we had asked if there was anyone we could talk to about our daughter's mental health and advice on how the family should deal with it. In all nine years we were never once offered help. Never offered the opportunity to discuss my daughter's diagnosis, or how this diagnosis was reached, even when it was changed by four different psychologists/psychiatrists over a period of two years. No-one asked us for any input, or any family history. Yet each time we were left to pick up the pieces with no information on how to handle this new diagnosis, no information on the medication and no mention of any aftercare. Each time we were left to sift our way through services to try and find appropriate care, in between hospital stays, for our daughter.

At the last hospitalisation, I remember I was given a book, from the mother/carer of another in-patient, who thought it might shed some light on things! After reading the book "I hate you don't leave me" I wondered why on earth something like this had not been suggested to us before. It answered so many questions for us and also helped to explain so much about my daughter's behaviour, yet it took another mother to point this out to us. Reading this book encouraged me again to ask for help.

I asked one of the nurses if there was any family therapy available where we could discuss my daughter's mental health, the behaviour and the impact it was having on the family. I was aware by now that there were some issues regarding my daughter's behaviour that seemed to hinder her treatment and her relationships with professionals.

Yet the more I read about border line personality disorder I realised that surely professionals should realise that when dealing with borderline personality disorder the fact that the patient moods change so frequently, and that some of their perceptions and interpretations become so distorted, surely it would help their treatment enormously if they were able to access consistent observations from loving family members over a prolonged period of time. Surely that kind of information would only help both the professionals and, more importantly, the patient. However, never were we asked to contribute to any of our adult daughter's treatment plan.

I believe, through this chance conversation with the young nurse, that I somehow came under the NSF Scotland radar.

The day we met with Highland carers' officer was a real turning point for us. For the first time in seven years were we able to talk freely and openly about our daughter, her illness, her treatment and the impact it was having on all of us. The carers' officer not only listened, but could truly empathise with us as he too was also a carer of someone with mental health problems. For the first time in years we did not feel judged, we did not feel as if we were to blame, we did not feel we were on our own.

We were given some terrific advice regarding encouraging our daughter into independent living and encouraging her to take on more responsibility for her treatment/recovery. Even though we deep down knew these things, to have them validated and to be told it was "OK" to do this was so heart-warmingly reassuring and what we so needed to hear. To also be able to speak to the carers' officer on the phone during the next few years when things went from being stable, erratic, crisis and back to stable with regards to our daughter's health, it was such a comfort to be able to be honest about things, not to feel judged, not to be told you were doing things wrong, but just to be listened to and encouraged and told that you were in fact doing the right thing; that you were not responsible for getting the right treatment for her, but that by always being there, being supportive and loving and accepting her, you were valuable.

In fact this was the first time, seven years after our daughter's first diagnosis, that someone had called me a carer. Was that what I was? I had to laugh to myself. I remember so many times, waiting for our daughter in yet another waiting room, looking around the walls, reading the odd leaflets, and wishing that I was a carer, they seemed to have so much support out there, whereas my belief was that parents were left out in the cold!!

Maybe it wasn't so much that the literature was wrongly worded, maybe it takes a certain time in your journey to realise, or for someone to tell you, that you are in fact also a carer. I so wish all psychologists/psychiatrists would tell the person who is mainly responsible for their patient's after care, that they are in fact a carer and as such entitled to any carers support available.

Anyway the carers' officer of NSF (Scotland) was a Godsend. There seemed to be so many times that he just seemed to call at the right moment. As most carers will recognise, we seem to walk about with a tight ball of tension most of the time. You can't release it by talking to just anyone, you feel so disloyal. However, the NSF

(Scotland) carers' officer would phone and after his phone call I would realise that the tension had lessened greatly, just by being encouraged to talk about things. So thank you, NSF (Scotland) because I don't know where I would have been without your support.

A few years later I received a call from NSF (Scotland) asking if I would be interested in attending a Prospect Training Course for Carers. Of course my first reaction was, is this not for "real carers"? Would I be taking a place away from someone who really needs it! Surely there must be someone more deserving of this! I am so glad that I was encouraged to attend this course.

Prospect Training for Carers: What can I say about this course? Well for anyone that knows me they will have heard it all before. I cannot praise this course highly enough. I do not have the grammar nor the vocabulary needed to do this course justice. So you will just have to bear with me.

Attending this course I was a bit apprehensive and scared. Would all the others carers be 'real' carers and have relatives that were far more in need than me or my family. Would the facilitators be patronising or condescending, telling us to breathe through our nose/ listen to sweet music and regain our independence? Would I be asked personal, awkward or embarrassing questions?

From the start the facilitators were absolutely fantastic. Each one brought with them their own compassion, insight, history that surely can only come from someone who has shared similar experiences - and survived. They were truly wonderful, and because of their own individual experiences, some which they shared with the group, it immediately made the group feel safe, valued, understood, which in turn encouraged every participant, and I mean every participant, to share, laugh, cry in such an intimate way in such a short period of time, it was a truly remarkable and life changing experience for every member of the group.

We each learned so much about ourselves, how to take back a bit of ourselves that had been lost throughout the years of coming to terms with mental health illness, battling with professionals, left dealing with problems/behaviours that we had no prior knowledge or training to deal with. Yet, each one of the battered, bruised souls that attended Prospect came away with a sense of healing beginning to take place.

So much so that when we met up again several months later, not only was it apparent in the way people spoke, thought, and in their attitudes that they had changed, but also in many cases even their physical appearance. Gone were the hollow, haunted, fearful expressions. Even though their circumstances hadn't changed, the way they felt about themselves had. What a truly wonderful course.

Everyone who attended the training has said the same. Life changing. If there is anyone with any clout out there and who knows of carers in need - then please get funding for this course and send as many carers as possible.

Being on the course empowered me to think about me, for the first time in years. It gave me the courage to then join my local carers' group. Having moved from the Highlands this was now the Dumfries and Galloway Carers' Group.

Once again meeting with the carers' officer for Dumfries and Galloway and knowing that she is on the end of the phone when things get tough is such an important part of what NSF (Scotland) offer. Knowing that she truly understands what is going on, and knowing that her advice is full of common sense, because, she too is also a carer.

It makes so much difference to a professional's understanding I think, when they can truly say I have walked, or I still walk, in your shoes. They don't try to "fix" it for us, they know they can't. They acknowledge our pain, they encourage us to see other ways of working through our problems, but most importantly they are there for us.

That in itself makes us feel important enough to go on and to keep trying. At the support group, again, this group of people, bound together through one common purpose, we love and care for our relatives with mental health illnesses and want to ensure that they receive the care they deserve. Yet we have some laughs, we learn from each other and hopefully we support each other.

It is so nice to be able to be part of this group and not be judged, not feel you have to justify yourself or your relative, but just to sit and have a natter and a laugh and through visits from professionals be kept informed, or inform them - if they have a heart and ear to listen - on treatments, care, new policies, strategies, for example. The ironic thing, that for some, this is the nearest they come to a social life, because it's the only time they don't feel guilty about leaving their relatives to come out and do something "for themselves".

So, nine years, and still, we are left to pick up the pieces when all our daughter's professional (and personal) relationships break down. We have seen the pattern over nine years. We have watched whilst the next new professional involved in the treatment of her care, decides on a different diagnosis, or a different bout of medication, and we have always had to be there when it all falls down again.

Would we want to change it? You bet! Would we like to work with the professionals in partnership, so that we can together help move my daughter forward into taking responsibility for her recovery, whilst having a consistent and caring professional working alongside her? You bet!

So please don't look at us and assume that we want or need or even in some way encourage this dependency. You bet not!

We would trade anything to be able to return to some kind of normality in our household, where we are not always having to respond to our daughter's illness/behaviour because there is no-one else she can turn to!

Our daughter now uses the NSF (Scotland) services for herself. She has seen the professional, consistent and reliable way that the NSF Scotland service has helped me over the last few years and I think it has encouraged her to trust and open up to what they have to offer. And we hope through their genuine understanding of borderline and other mental health issues and the empathy of the staff, which seems to be a pre-requisite of working with NSF Scotland, that she is able to work with them on a long term basis towards becoming more responsible for her own recovery.



So next time you are sitting in front of a carer/mother/father/sister/brother/wife/husband/child please don't make assumptions, instead listen to them. And if you can't or won't listen to them, please inform them of NSF (Scotland) Carers' Group or other such groups. Don't leave them hanging - it's too cruel

## **12. Mary: Carer for her teenage son who has a learning disability**

My name is Mary and I am a parent to my son of 18 years who has a learning disability, challenging behaviour and autism. My husband and I both work as teachers which keeps us extremely busy. We are in our late fifties. We have found that society has struggled with our son ever since he tried to fit in at primary school. We really despaired for his future as he approached the transition into adulthood.

Caring for our son was placing a strain on our relationship, our employment and our health. We were both physically and mentally exhausted. We never had a holiday without the stress of caring for our son. Our son has damaged his room, our bathroom and other areas in the house. We had to purchase sturdy furniture and fittings to sustain the damage.

However with this new respite service the local area co-ordinator visited us in advance of using the service and we designed a short break holiday specifically around our son's needs guided by his and our experiences. For the first time we were able to take a holiday and it was brilliant.

Don't get us wrong. At first we felt guilty but quickly realised that the break re-energized us and made us happier as a family. Now we take planned, longer breaks, at least twice a year as the respite is flexible and we have recently taken our dream holiday to Italy for two weeks. We still face many challenges ahead but my son enjoys his break and we enjoy ours and it makes for a happier family.

### **13. Carer: Carer for several members of family with various conditions**

I care for/support several members of my family; an elderly aunt, my mum who is 79 and has Lymph Cancer, Peripheral Vascular Disease and Epilepsy amongst other conditions. My father who is 84 and suffers from Emphysema and has been in hospital five times this year, so far, and a elderly aunt needs my support intermittently. I also share care with my cousin for another aunt who has Alzheimer's disease. She stays in North Lanarkshire.

I've lived in England for the last 33 years and decided to move back to South Lanarkshire eighteen months ago before the five hour drive every time one of my family was ill became too much. My family all have care packages in place. I feel it is my role to ensure they receive the right care package. The other things I do for them, if needed, are shopping, washing, ironing, escorting them to hospital, dentist, bank appointments as well as providing any advice they ask for. I am also Power of Attorney for all four of them. For me, it is all about planning, organisation and prioritising within the people I care for. When I lived in England I worked part time as a Human Resource Consultant and part time as a Complementary Health Therapist. I have managed to fit my caring role around my HR Consultancy but have been unable to continue with my complementary health therapy. By planning in advance I manage to meet up with friends and still have some social life.

As far as my health is concerned, my previously good diet and eating habits have suffered and I now find myself eating the wrong foods at the wrong times and sometimes feel very low. What do I get out of it?

Knowing what I am doing is giving my family a better quality of life and removing worries that they would otherwise have. It would help if some of the processes were not so time consuming. It would also help if there was a better understanding from health professionals. For example; when applying for renewal of my aunt's blue badge who, as well as having Alzheimer's, has had two hip replacements and suffers from oedema, making it difficult for her to walk, the doctor didn't get in touch with me when looking over the forms I had completed.

He called my aunt, with Alzheimer's and she told him there was nothing wrong with her. The application was therefore declined. Despite writing a letter to the GP asking him to re-consider, the application was still declined. At that time I didn't have the energy to fight it so I left it for six months, made an appointment with another GP and went through the whole process again. This time he wholeheartedly supported the application

As a carer I was unconsciously incompetent and didn't know what I needed to know. With advice from a friend, I looked on the internet for carer information and found South Lanarkshire Carers Network. I called the office to find out about the monthly carers' meeting and now attend regularly. I have learned a lot from speaking to other carers and especially from the speakers. The network has been a Godsend to me. It gives me peace of mind to know where I can get the information I need.

#### **14. Carer: Carer for mother who is partially sighted and father who is terminally ill**

I started caring for my mother when she became partially sighted ten years ago. She is now 79. She can no longer go out on her own. My father has stomach cancer; he is terminally ill. I have three sisters and they take my mother for her shopping twice a week. I look after my father when they are out. There has to be someone with him at all times and to receive medication being delivered from the pharmacy.

My parents have a very good care package in place which gives me peace of mind knowing they are being cared for when I or other members of my family are not there. I have my own disabilities. When I was five years old (I am now 46), my sister and I were knocked down by a car. She didn't have any serious injuries but I received serious head injuries and was in a coma for six weeks. As a result of my injuries my mobility is affected; I have difficulty walking and despite receiving physiotherapy I can't do much with my left hand. I also take medication to prevent me from having seizures.

Thirteen years ago I moved from my parents' home into my own home. I was assessed by the occupational therapist who recommended various adaptations, for example, ramp, handgrip bars, walk-in shower and shower seat. Having these items means I can live independently in my own home. I am involved in several voluntary organisations; I provide admin support for South Lanarkshire Disability Forum which is a voluntary organisation run by and for disabled people in the community, it provides free and confidential information services. I am a former committee member of Headway which provides support, advice and information to survivors of brain injury, their families and carers living in the South Lanarkshire area and I have been a member of South Lanarkshire Carers Network since the beginning. For me it's a two way street, I receive useful information from these organisations and I also have information to pass on which may be helpful to other carers.

## 15. Two Carers: Who were carers for their mothers who both had Alzheimers

- a) I cared for several years for my mother who had Alzheimer's. This was in the 1970's when there was little or no help or support available to carers. I took my mother her meal every evening and made sure she was ok. At this time I had a busy family life, I was married with four daughters of my own and a full time job. Things have changed greatly since then. My wife May and I cared for my mother-in-law, who also had Alzheimer's disease. The services through South Lanarkshire Council and carers organisations we were able to use were a great help to us, in particular receiving a carer's assessment opened many doors. Sadly my mother-in-law died in 2007.
- b) I have coped with Rheumatoid Arthritis since I was a youngster. I also suffer from hyper joint mobility which results in me being unsteady on my feet and prone to falling. Mum was showing the early stages of Alzheimer's disease. By this time my four daughters were independent and had left the family home. Campbell and I received a carer's assessment and through this we were able to secure more home care and some adaptations in her home such as the installation of a shower; she also attended a day care centre which allowed me some respite.

My mother had a fall and broke her femur, she spent thirteen weeks in hospital during which time her condition vastly deteriorated. When she came home my caring role intensified, as she was very disorientated and required lifting and handling. I was horrified at the mention of her having to go into a care home, I felt a great sense of duty as a daughter to ensure that I looked after her. I didn't realise I was a carer "I was just looking after my mum". I continued to care for her at home with the help of Campbell for a few more years. My own health deteriorated, taking advice from my doctor and our social worker I was eventually persuaded to allow her to go into a care home.

At first the care home was very good, however there was a change of ownership three times during her stay which created a few problems. Because of this we started a carers' group. We met at the home every month with the sister and some of the care home staff. As a result, improvements were made. There are many who have helped me through my caring role; South Lanarkshire Council social workers for their support and good advice, Rutherglen community carers who looked after me emotionally and South Lanarkshire Carers Network who built up my confidence which enabled me to speak out. It is reassuring to know I have somewhere to go with any issues I have. During my mum's illness holidays were not an option for us. Even when she was being cared for in a home, I wanted to be close at hand. We have a caravan in Dunoon and used that for short breaks. I am pleased to say we are going to Florida this year, our first holiday in six years. We are now in the position to see more of our daughter, son-in-law and grandchildren who live in England

Campbell and I are still actively involved in Rutherglen community carers and South Lanarkshire Carers Network. I am a past carer and continue to cope with my own health problems. Campbell is once again a carer for me.

## **16. Parent Carer: Cared for daughter who had cerebral palsy**

Prior to my daughter Leanne being born in 1981, I worked as a Dental Nurse, then went on to become self employed as a beautician. When Leanne was born I was quite happy to leave the workplace behind for a short time to be a full time mum. At around seven months old it was picked up during routine assessments that Leanne was not responding the way a baby should. I was later told she had cerebral palsy, she was mentally and physically handicapped. It took me about a week to digest what I had been told. I was then to discover a realm which was unknown to me. My life started to fill up with clinic and hospital appointments, I felt very vulnerable. My marriage broke up when Leanne was eighteen months old, our house was sold and Leanne and I moved into council accommodation. I spent the next five years as a single parent. I tried to get back into the workplace but with Leanne's needs it was just too much. I met my husband Alex when Leanne was six years old.

My caring role put me under considerable stress. Due to Leanne's irregular sleeping pattern I often found myself sitting down to my main meal in the early hours of the morning, as a result I gained weight. Leanne had scoliosis and had to be lifted, I suffered from extreme frozen shoulders and still have recurring shoulder problems and weakness in my arms. I was unable to bear the strain of lifting her so Alex had to be on hand, he too became a full time carer. There is also the isolation involved with being a carer. I couldn't make arrangements with my friends because I didn't know how well my daughter would be on any particular night I had arranged to go out, she always came first. Often as a carer you are not able to earn a living which in many ways removes your freedom of choice and can make you feel very vulnerable and isolated. Carers don't want to be made out as heroes, they just want to be parents, partners and friends.

We managed to secure a Margaret Blackwood bungalow (a specially adapted house for disabled people) and a motability car. Leanne died just before her seventeenth birthday. As well as coping with the shock and grief of losing my daughter, we had to give up our home, our car and our income. I went from being a carer one day to an unemployed person the next. I felt mentally and emotionally exhausted for quite some time and needed time to feel better in myself and overcome some of my health issues. It was five years later when I returned to the workplace which was extremely daunting. Last month I started a new job as Training Officer for the Network. My role will enable me to enlighten service providers and to give them some understanding of how their job helps support carers and how vital their role is in making carers' lives easier. I am heartened to see there are systems in place that are more receptive to what carers' needs are and more possibilities are opening up. Together we are all looking for a better way forward and I am glad to be part of that.

I am still on my journey.

## **17. Parent Carer: Carer for two sons both who are diagnosed as profoundly deaf**

I have three children, David, Stuart and Craig. David was three years old when Stuart was born. When I took Stuart for his ten months assessment, he did not respond to hearing tests. At the audiology clinic in Hamilton Stuart was found to be profoundly deaf. At one year old, Stuart was wearing hearing aids in both ears. There was no deafness in the family. I was told it could have happened as a result of being in contact with a Rubella carrier and the chances of the same thing happening were a million to one.

A peripatetic teacher visited Stuart at home up until the age of four. She used specialist equipment to teach him sounds. He also attended nursery within the deaf unit at Craighead Nursery School. The most traumatic day of my life was when I had to put Stuart, age four on a bus to attend school at 8.30am until 3.30pm. At age six he attended the deaf unit at Glencairn Primary School where small classes of deaf and hearing children were integrated. There he progressed really well. At this point my third child was born, Craig. At nine months old it was discovered that Craig was also profoundly deaf (so much for one in a million chance of happening again!). After I had recovered from the shock, I decided that my philosophy was, the boys were children first and deaf second.

It was a constant worry to me that they couldn't hear danger, everyday things that children do like riding a bike were not safe. It was difficult and frustrating trying to teach the boys lip reading and speech. You had to be face to face with them constantly. I had to spend additional time with Stuart when David was only three and at times he felt left out so I had to try to make up for it. We received invaluable help from the National Deaf Children's Society. David is now 35, married and is a Lecturer at Glasgow University, Stuart is 32, married and is a teacher of sign language to hearing people and Craig is 26, married and is a spray painter. I say, the fact that your child has a disability doesn't mean that they are not going to make it in life. At the time, I didn't think that I was a carer, only a mum. It wasn't until I heard about South Lanarkshire Carers Network that I realised that I was a carer.



## **18. Carer: Carer for several members of family and son who has a mental disability**

I've been a carer for most of my life. I got married at sixteen years of age. I had six children, five boys and a girl. Two of my children died, one of my sons died at ten months old - John, my other son died in 1991 aged twenty one - Gary.

Gary was using drugs so I learned a huge amount from the drugs world which I had been totally unaware of up until the day it came to my door. By the time Gary was sixteen he was diagnosed with HIV, which was in 1984/85. For the next five years I was at a loss in how to deal with the virus as at that time there was no information available to me or my family. My caring role resulted in changes to my entire life. I had to take time off work and change my shift patterns; luckily I was supported by my employer at the time. My other children were receiving less and less of my attention which caused problems at school; they became withdrawn and fell behind with their homework. After a meeting with the school they supported me by providing the children with extra tuition which was a huge relief to me. As time went on I became very isolated with no social life at all. Gradually my friends and neighbours drifted away and I had less and less contact with the outside world.

In addition to the above I had other caring roles within my family at different times in my life. I cared for my mother who died of cancer at a very young age, my two brothers-in-law who both died of cancer, currently I care for my twenty four year old son who has a mental disability. I think I was meant to be a carer! The great thing is, there has been such an improvement in services, information and support to people like myself and all carers no matter who they are caring for. Things change in life and there is always room for improvement. Because of my experiences, I am able to help and support others in the same situation. I was a co-founder of HIV-AIDS Carers & Family Service Provider Scotland seventeen years ago. Our organisation has grown through the changes in needs which vary from person to person. We provide support for the whole family.

I feel all of the above would never have been put on my shoulders had I not been able to carry it and it's made me the person I am today.

## **19. Carer: Carer for partner who has mental health problems**

Brian is a carer for his partner Martin who has mental health problems. Martin has been in and out of hospital on several occasions but Brian has never been recognised by healthcare staff as being Martin's partner or his carer. In fact healthcare staff have often assumed that Brian is a friend and have not included him in any discussions about Martin's condition or care even though Brian accompanies Martin to doctor's appointments and ensures that he attends the hospital and dentist for treatment.

Brian and Martin were treated differently to heterosexual couples who meet in a private space during visiting times whereas Brian and Martin had to meet in the dining room of the hospital ward and one day when Brian put his arm around Martin to comfort him he was told to stop by healthcare staff as they thought this may lead to 'other things'. As a very private person Brian was extremely upset and humiliated. As Martin's partner and carer he was trying to reassure Martin that all would be well as Martin was very frightened and nervous about being in hospital at that time. On another occasion Brian was told by the psychiatrist treating Martin that relationships were not encouraged. Brian again felt that he was being treated differently because of his sexuality.

Once Martin was discharged from hospital to live alone in supported accommodation Brian continued to help Martin with everyday activities and chores. Martin's condition deteriorated rapidly and whilst there were a lot of promises made by healthcare and social work professionals these were not fulfilled. Brian became more stressed by the worsening situation and lost confidence in his abilities as well as those who could have helped him and Martin. However Martin's outreach worker was very helpful as she acknowledged Brian's role in Martin's life. With Martin's permission she included Brian in the discussions around Martin's care which enabled Brian to learn how to deal with some of Martin's challenging behaviour. Brian felt that his role was being acknowledged and that there was someone he could ask for advice if needed. Recognising Brian and Martin's relationship was essential in supporting Brian to remain in a caring role as Brian was able to seek support for his own needs without feeling judged or discriminated against.

## **20. Carer: Carer for husband with multiple sclerosis and has a son with physical disabilities**

I am 52 years old and my husband is 58 years old. We were married in 1984 and my husband was diagnosed with multiple sclerosis a year or two later. Although he had symptoms for some time, in the last five years they have worsened considerably. We have a 13 year old son.

My husband was a Church of Scotland Minister and I am trained as both a primary and secondary school teachers. We have both worked as a team in the parishes we have served for more than 25 years in both our professional capacities and also in a voluntary capacity where we have encouraged communities to work together and support each other and through a variety of projects.

Over the past four years my husband's condition deteriorated to such an extent that he had to retire on health grounds. We had bought a flat for our retirement in Edinburgh, but had to sell this as we could not pay for a mortgage when my husband retired. Fortunately the Church of Scotland provided us with a flat in Inverkeithing and we rent this from the Church of Scotland at a reduced rent.

Our income was severely limited when he retired as we only had this pension of £11,000 per year. However, because we sold the flat this meant that our savings exceeded the amount to claim other benefits. We were on the borderline for income.

I had previously worked five years part time in administration for the Holyrood Trust in Dumfries and did voluntary work.

In 2006 I began full time work at Edinburgh University as Departmental Secretary in the Medical Teaching Organisation and was a carer for my husband who was now becoming wheelchair bound outside, and very limited in his walking and motor skills. I have osteoarthritis and had several operations when I was a child which meant that I walked with a limp and suffered chronic pain. During the year of 2007 my chronic pain increased and my muscle spasms increased to such an extent that I had to be signed off to recover and this happened with increased frequency, I asked if I could change my employment status to part time but that was not possible due to the nature of my job description which required one person to do the administrative tasks. I went into work for 8.00am and stayed often until 5.30pm, and I worked on holidays remotely at home to keep up with the administrative tasks. However, I found that the physical demands became too much and I resigned on grounds of having to look after my husband as my caring responsibilities increased.

I returned to supply teaching in the Primary sector in Fife in December 2008. Once more this began well, however my own osteoarthritis became worse and I again had more chronic pain and increased muscle spasm which ultimately lead to my left knee becoming so worn that the bones rub constantly and I cannot work without the aid of two crutches. I cannot stand for longer than ten minutes and must constantly change position as the pain is constant 24 hours now. I have had to take increasingly stronger pain medication over the last four years which has impacted on my concentration and ability to work. I have applied for DLA Disability Living Allowance for myself and this was a difficult decision as I am an independent person.

I was told that arthritis was not covered by DLA, however my arthritis has caused pain, lack of mobility and I am unable to do normal things like cooking, or vacuuming and have personal care needs myself now. Due to having to push David in a wheelchair my back and muscles which were already compromised has meant that my disability has deteriorated more rapidly.

Over the last five years my disability has increased to such an extent that I cannot push my husband in a wheelchair. I wrote to our local MP Willie Rennie, who brought up the matter with the NHS Executive in Fife to ask for a powered wheelchair for my husband. The rehabilitation team in Cameron Hospital have been superb with putting raised chairs, perching stool and shower stool in our flat which has helped. It was not possible to get a powered wheelchair due to present NHS criteria which means that my husband is increasingly housebound as I cannot take him out. He cannot drive now, and I am the main driver with our Mobility car.

I do not blame the NHS or the GP or medical staff, they work within policy decisions which are decided by Government or by Management teams. However, I feel that because I am increasingly disabled there is not a policy process by which this is taken into account by the social work department and NHS to take my deteriorating needs into account for caring needs for my husband regarding his mobility. We are both now unable to walk far and increasingly less mobile. Through the handling and moving team through Fife Young Carers we feel that we are being listened to and supported. I feel that because we have double difficulties this means that we do not slot into normal parameters for support as a carer and the strategies and policies regarding access to mobility equipment, namely the electric wheelchair, are too strict which means that we fall outside the criteria. Similarly with the benefits process it is inflexible and does not take into account the ability not getting out of the house to attend meetings. Is there a phone system to access benefit advice?

I have tried to work and support our family through a severely stressful period and find that this has impacted on my physical health. The doctors are tied by the criteria relating to access to a powered chair. Our GP also wrote to the wheelchair assessment unit, and it was stated that we do not fit the requirements for a powered chair. I also contacted the social work department as our GP suggested that if I need to go into hospital then my husband will need more support at home. I found that the point of contact was not helpful as she asked what my assessment needs were for caring for him. I could not tell her as I felt that we needed a full assessment of our needs. It was a difficult phone call, and I felt that there was no point of contact to listen to my needs and it was up to me to assess our needs. This is rather difficult as I do not know how the social work department could help, or what facilities were available. How can one assess one's needs if they don't know how the social work department can help?

I am unable to do general housework so we pay a cleaner to come in once a week, out of our savings. We live off our savings, for normal needs, and do not qualify at the moment for either child tax credits through a mix up in their department, over assessing our needs. I have worked all my life and support the communities we live both professionally and voluntary. Now I feel that when I am in a difficult situation through ill health for my husband and myself we fall through the cracks, find difficulty in negotiating the system, or that because we are not elderly we fall between support

systems. There is no joined up system. When I went to the job centre to look for work and ask what benefits there were, I got more information from the security man than the staff, as they could not see me. I asked for support from the Disability Team at the Job Centre and eventually after months got a phone call to say that they could provide an access course. This course was unsuitable for me, as I know how to write a CV and present myself, I have multiple skills. The difficulty was that I could not physically keep working full time, or part time as my chronic pain increased and my mobility decreased.

I am a positive person but trying to navigate the benefit system is almost impossible, and as we use our savings for normal living, it means that we drop between the cracks. That is how I feel and would like to relate my story to the National Strategy team.

Trying to negotiate the benefits system, social work department and NHS policies has led me to feel demoralised. I am a fighter and have found support through Fife Carers and my son has benefitted greatly from the Young Carers, without this support we would have felt totally demoralised.

Please think up a more joined up system for claiming benefits, or access to more physical supports. It has been a nightmare to try and negotiate the benefits and the support system, especially in a time of crisis.

My son also has physical disabilities as he was born prematurely, and we have negotiated the help required through the education system as I am a teacher and knew how to access support and evaluation. Elsewhere the situation is horrendous as I am given conflicting answers. In the end I gave up trying to access benefits, as it was so complicated. We are currently trying to find out if we can access housing benefit, as our income is increasingly cut, as his pension is reduced over the years and I only get carers allowance. The tax credits system is not good, and because of administrative problems we are not eligible as they awarded us too much child tax credits on paper, we never saw the money, and then paid it back on paper through not receiving tax credits for the past five years, or more, we will be eligible in March 2010 or 2011 I think.

We never had a large income and we saved all our lives, as we knew that he would retire early. I worked when my physical health allowed over the years, and now we feel penalised by all the red tape and bureaucracy. Please slim down the system and make it more joined up, across NHS policies, social work support, and the benefits system. Also think of support for carers who are also disabled as well as the other partner or friend who is cared for

## Young Carers Stories

### 21 Sibling Carer: Carer for brother who has undiagnosed Dysmorphic Syndrome

I help to care for my brother Peter who is 15 years old. He has undiagnosed Dysmorphic Syndrome which means that one of his legs is smaller than the other and his leg is turned inwards. Peter also has learning disabilities. I have two younger sisters, Lisa age 12 and Alison who is 9 years old. I am Peter's interpreter when he needs one. Whenever he is unsure about anything he comes to me and when the situation arises, I calm him down. When Peter goes out he needs a splint for his leg so I put that on for him.

Mairi's mum Caroline describes her daughter as having an old head on young shoulders. Despite her own disabilities, she wears hearing aids in both ears and she suffers from asthma, she helps Peter instinctively. She is a caring person to anyone she recognises as needing support. At a time when Caroline was ill Mairi, then aged eight, helped to look after the whole family. As well as doing well in her subjects at school, especially in maths and English. Mairi is involved in the school choir and is editor of the school magazine for which she received the Alexandra Stark Award which is presented to a child who gives excellent community service to the school. If it wasn't for being a young carer I wouldn't know how to cook. I love cooking and would like to be a chef one day, or a fashion designer or a teacher.

It makes life easier that I have really good friends who understand that I am a carer. They explain to other children why I have to go straight home from school. They are quite envious of the club I go to, Universal Connections in Rutherglen which is a centre run by South Lanarkshire Council's Youth Learning Service where young people are encouraged to take part in lots of fun learning activities such as go-karts, paint ball, going to the cinema and cookery. There is also an art group and a girl's group which I take part in. It's a great place for me to get away from it all and for me to be me. I know of other children who are caring for someone but have not been identified as young carers. I think part of the reason may be that they don't want to be different from everyone else they just want to be the same as their peers or they are afraid of being bullied.

I think it would be useful if there was more information in schools and health centres giving the definition of a young carer and telling them where they can go for support. I hope that if any young carer reads this, it will make them realise that they too are a young carer and encourage them to ask for the help and support they need.

## **22. Graham: A young carer for both mother and younger sister**

Graham lived in a family household with his mother, father, older brother and younger sister when he was referred. Graham's father was the main carer until he died very suddenly in January 2009. As a result, Graham is now the main carer for both his mother and younger sister. Graham's mother has chronic renal disease requiring dialysis three times a week. Mum has to leave the family home at 6am to attend appointments for dialysis. Graham has then to go and meet his mother after her dialysis as she often feels unwell and weak.

Graham's younger sister has cerebral palsy as well as learning difficulties and wears hearing aids. She has major tantrums and these have worsened since the loss of their father. Graham has the responsibility get his younger sister up for school, washed, have breakfast, dressed and ready for the taxi to collect her for school.

Graham had poor attendance leaving school early without any qualifications or a career plan. Through involvement and support of UPBEET Graham identified various goals to work towards. The main areas highlighted were working on a huge lack of confidence and self esteem, isolation, personal mental health issues and self harming. Graham also mentioned he would like to go to college but dreaded the thought of meeting new people as well as worrying about his academic abilities and managing his caring role.

One of the major impacts through UPBEET for Graham was receiving intensive one to one support. Through one to one sessions Graham worked on his confidence and self image by experimenting with new experiences he would never have dreamed of doing before, for example, visiting colleges to have his hair done and enrolling in taster courses offered by the college. The agenda was to work on Graham's confidence to feel comfortable attending college appointments and meeting new people. Through this piece of work there were visible signs of improvement on his own personal appearance, personal hygiene, confidence and attitude and motivation towards thinking about getting a job or attending college.

Graham felt confident enough to attend a local training provider which focused on getting ready for work. He stayed there for a short time until he was accepted for college. Graham then went on to study part-time at Dundee college but started to get anxious and lose confidence after missing a few days due to issues at home. He avoided going back to college due to the fact that he was too embarrassed to see his lecturers. The UPBEET staff worked to help Graham through this dilemma and he is now back studying open learning through the college.

Graham's confidence continued to grow with him enrolling at a local gym, and he is now trying to work on reducing his weight and improving his fitness levels. Graham has attended information sessions on healthy eating in relation to foods and mood – the aim being to help improve his own mental health.

Graham is now participating in group sessions allowing him to have a new network of friends and fun through UPBEET. Through attending these group sessions Graham has gained his Bronze Youth Achievement Award, First Aid Certificate, Assertiveness Training and a REHIS elementary food hygiene certificate. The



outcomes achieved have been overwhelming for him. Graham has recently been away on a three day residential giving him respite from her caring duties, allowing him to have three days of new learning experiences and most importantly lots of fun. He is now planning to get back to his studying and is hoping to complete his Silver Youth Achievement Award before the end of this year. Graham is now part of another group helping to set up a young persons LGBT service in Dundee.

In addition to providing one to one support, Graham's keyworker also signposted and referred him on to more specialist interventions to help him cope with the traumatic loss of his father.

UPBEET have also put in place a family support worker for mum and this has had a huge impact for mum and the whole family. The worker was able to get the family's care package reassessed, with carers now going in to the home to help in the mornings with the younger sister and easing a bit of pressure for Graham. The family support worker was able to give additional information of groups and after school clubs in their community for Graham's younger sister. Mum still has major concerns which are causing her a lot of worry, but now has a dedicated worker to talk to instead of putting all her worries on Graham. Their relationship is now getting a little better and Graham is slowly coming to terms with changes in his life.

### **23. Donna: A young carer for mother**

Donna has her own health issues including anxiety attacks and agoraphobia. Donna's caring role has, at varying points in her life denied her positive socialisation experiences. As a result she struggles to interact with peers and lacks age appropriate experiences in a social sense.

Donna's mother has mental health problems, and due to her mental state tends to stay in bed most of the day. When she is up, it tends to be in the early hours of the morning, mum is in the habit of singing and waking Donna out of her sleep for company. Donna's caring responsibilities include organising the house, shopping, cooking and cleaning. Recently Donna had to organise a house removal due to the family being decanted from their previous home. Donna had to arrange most of this on her own including organising times for workmen to carry out work in both premises. This was a lot of work as there was only a two week time scale and there were extreme difficulties due to Donna's mum being very suspicious of new people, making it harder for other support to be in place for them both.

The areas of intervention we addressed with Donna were social interaction, confidence building, communication, problem solving and mental well being. Working with the medical professionals, we aimed to help support Donna to overcome her anxiety attacks and overcome her agoraphobia as these were huge barriers to getting back into work, education or training.

Through involvement with UPBEET Donna has been able to access one to one support. This support has had a positive impact helping Donna address the goals she set herself. Initially Donna cancelled one to one sessions fairly regularly due to her caring role and her own health problems. However, this was addressed with the keyworker and Donna's attendance has become far better over the course of her engagement with the project.

Donna now leaves the house and interacts with group sessions. She has taken part in UPBEET residentials – a huge challenge for her. Through involvement with UPBEET Donna has now made friends of her own age indicating her social interaction skills have improved. Donna values her one to ones and feels it really beneficial to speak to someone as her mother can really infuriate her at times. Donna completed a REHIS Elementary Food Hygiene certificate through UPBEET and used this for evidence for her Bronze Youth Achievement Award. She was accepted into college and also supported to apply for volunteering posts and employment.

The impact on Donna's mum has been more manageable with Donna working part-time and volunteering as she can work around her mum's needs and demands of her. UPBEET have offered family support for mum but that has been declined as mum is still suspicious of new people and no one gets into the house. Donna tells me her house is a shambles as mum won't let any workmen in leaving Donna to assemble all the furniture that gets delivered via online. UPBEET have tried to organise for a council handyman to carry out work to help the family but mum will not allow it to happen.

Donna is more confident within herself. Her anxiety attacks rarely happen now allowing Donna to have a better quality of life, go out with friends and have fun when mum allows this. UPBEET continues to support Donna on a one to one basis that is still a priority for Donna to continue to cope with her caring role. The work with Donna has been very much up and down over the course of her engagement, with lots of hurdles along the way, but the keyworker is confident that UPBEET is achieving the goals established with the client, especially overcoming the barriers to accessing work, education and training opportunities.

## **24. Jenny: A young carer who provided care for family during father's terminal cancer**

The UPBEET Project started supporting Jenny, a 16 year old girl, while her father was suffering with terminal cancer. As the eldest sibling in a family that had only moved to Dundee a few months earlier, Jenny felt a strong sense of responsibility within the family unit and was struggling to engage with education at the time of her referral. Her keyworker helped to support her through her dad's eventual death, and is still involved helping Jenny to cope with her bereavement and to move on with her life.

The main focus of the work with Jenny has been a consistent keyworker through UPBEET who has been able to provide regular one to one support and space to talk through her issues. Through the one to one support, Jenny has been encouraged to set her own goals. These included working towards and gaining a Youth Achievement Award, then helping to plan and do a presentation at the Awards Ceremony with the Lord Provost of Dundee. She also undertook a Food Hygiene course that gave her a recognised qualification and helped to build her confidence. Through the wider services of the Dundee Carers Centre, Jenny was also able to access Welfare Rights advice and open an account with a local Credit Union, which has helped her to become more financially independent. She has taken part in two residentials, helping to plan them and also taking on responsibility for catering.

Jenny's keyworker has also made appropriate referrals on to a specialist bereavement agency for young people and to a local training provider.

The work with Jenny has made a noticeable improvement in her social skills and in her levels of confidence. As a result of the intervention she was also helped to sustain part-time work while studying and achieved very concrete and measurable goals. She has now attained a full-time place at Dundee College and is making real forward progress in achieving her goals.

In terms of the impact on Jenny's family, the support from UPBEET has been beneficial in enabling her to cope with the strain of caring for her terminally ill father and giving her space to talk through her feelings.

The work with Jenny up till this point has been very successful in achieving the aims identified by the young person. The main goal for all UPBEET clients is to work towards some kind of positive destination, enabling them to manage their caring role so that they can access some form of education, employment or training opportunity. The consistency of the intensive support from UPBEET has helped Jenny to cope through a very difficult time for her and her family, and to re-engage with her education when she could have struggled to move forward with her goals.

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